

# MENTAL HEALTH DIAGNOSES IN PERSONS WITH AN INTELLECTUAL DISABILITY: HOW HEALTH PRACTITIONERS OVERCOME THE CHALLENGES

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A thesis submitted in partial fulfilment of the  
requirements for the Degree  
of Master of Science in Psychology  
in the University of Canterbury

by Karen P. Davies

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University of Canterbury

2015

## ACKNOWLEDGEMENTS

Firstly, I would like to thank my primary supervisor Dr Eileen Britt from the Department of Psychology, University of Canterbury. Thank you for helping to guide me through balancing the demands of the Clinical Psychology Programme whilst also conducting research.

Many thanks also to my secondary supervisor Chris Daffue from the Intellectual Disability Service, Canterbury District Health Board. Your expertise in the ID field and passion for helping clients is truly inspiring and keeps me striving to improve myself as I continue the journey to becoming a Clinical Psychologist.

To my parents Bernie and Baz, thank you for all of the love and support which was unwavering throughout this journey. Escapes up to Whangamata to relax at home and on the beach were very much needed! To my brothers Geoffrey and Michael, thanks for keeping me laughing and life light.

To my amazing friends Lucy and Milesa, thank you for all of your support as I have found my feet in Christchurch. I don't know what I would do without you girls!

Thank you also to the participants that shared their experiences, and the organisations and clinicians that helped in accessing these participants. Without you, this thesis would not have been possible.

Finally thank you to the individuals who inspired me to begin research in the ID area. I feel so privileged to have been a small part of your lives, both in a support caregiver role and hopefully as a health practitioner in the future.

## **ABSTRACT**

Legislative changes in line with changing societal perspectives have resulted in increased service pressure on primary health practitioners to take further responsibility for the assessment and treatment of co-morbid psychiatric disorders in individuals with intellectual disability (ID) and for secondary and tertiary level services to reduce waitlists. The unique attributes of the ID population and a core lack of training for health professionals in the ID field has resulted in a large number of practitioners feeling under-trained and under-resourced to carry out this role effectively, to the potential detriment of the ID population. The challenges health practitioners experience when diagnosing co-morbid mental health disorders in individuals with ID and how they overcome these challenges was explored in this study. Participants were health practitioners of varying professions, including Psychiatrists, Clinical Psychologists and General Practitioners. Health practitioners completed an online survey and/or partook in a focus group or individual interview. The method used in this research was thematic analysis. The study found that health practitioners use holistic and contextual approaches to carry out assessments of individuals with ID, utilise ID specific tools, and liaise with experienced, specialised health practitioners as ways of dealing with the complexity of diagnosing co-morbid mental health difficulties in individuals with ID. In addition, it is recommended that more training in the ID area is provided for health practitioners, particularly for GPs in light of recent policy changes with emphasis of assessment and treatment occurring at the primary health level and for best practice guidelines to be developed. A further research project is suggested, exploring specific challenges facing GPs in this area of practice.

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## **CHAPTER ONE – INTRODUCTION**

### **1.1 Intellectual Disability**

Intellectual Disability (ID) has been referred to by many different names across history. Over time some terms have fallen out of favour with others taking precedence. For example the term Mental Retardation has largely been replaced due to the negative connotation now associated with the term. This has only been a recent change however as it is the term referred to in the Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR) and the International Classifications of Diseases-10 (ICD-10) (American Psychiatric Association, 2000; World Health Organisation, 1992). Within different geographical parts of the world ID is referred to by varied terms. In the United Kingdom the term Learning Disabilities is often used to describe ID (Michael, 2008). It is important to note that this is a separate diagnosis from Learning Disorders. Within New Zealand (NZ) the term ID is most commonly used. This is reflected in governmental policy, legislation and guidelines all of which refer to ID (Ministry of Health, 2011; Ministry of Health, 2013; Ministry of Health, 2015). The terminology a health practitioner uses may potentially impact upon how they view and understand an individual and the difficulties they experience. For example in the DSM-5 whilst the term ID is used, it is called Intellectual Disability Disorder. The word disorder implies something is problematic and as such requires fixing. However, this directly contradicts the life long course of ID and the efforts of many to normalise the experiences of individuals with ID. For the purpose of this thesis only the term ID will be referred to in line with NZ policy and current understanding of the appropriate terminology as outlined by the American Association on Intellectual and Developmental Disabilities (AAIDD) (American Association on Intellectual and Developmental Disabilities, 2013).

There are a number of different definitions that are used by different resources/manuals to define ID. There is also continued debate as to which of these is the

most appropriate. It is important to consider the issue of varied definitions as the manual a health practitioner chooses to follow may impact on whether they consider the individual to have an ID or not, or to what extent the ID impacts upon the person. The Diagnostic and Statistical Manual of Mental Disorders-IV-TR (DSM-IV-TR), Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-5) and International Classifications of Diseases-10 (ICD-10) are among the most widely used. The DSM-5 is the most recently released of these, however support of it is varied and many health practitioners continue to debate its scientific basis and usefulness (Belluck & Carey, 2013).

According to the DSM-5, an ID is defined as a neurodevelopmental disorder characterised by both intellectual and adaptive functioning deficits in conceptual, social and practical domains (American Psychiatric Association, 2013). It describes deficits in intellectual functioning consisting of “reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience” (American Psychiatric Association, 2013, p.37). These difficulties have to be confirmed by both clinical assessment and individualised, standardised intelligence testing (American Psychiatric Association, 2013). The conceptual domain is defined as consisting of “memory, language, reading, writing, math reasoning, acquisition of practical knowledge, problem solving, and judgement in novel situations” (American Psychiatric Association, 2013, p.37). The practical domain is defined as consisting of “learning and self-management across life settings, including personal care, job responsibilities, money management, recreation, self-management of behaviour, and school and work task organisation” (American Psychiatric Association, 2013, p.37). The social domain is defined as consisting of “awareness of others thoughts, feelings, and experiences; empathy; interpersonal communication skills; friendship abilities; and social judgement” (American Psychiatric Association, 2013, p.37). As with intellectual functioning, deficits in adaptive functioning are assessed by both clinical evaluation and individualised,



culturally appropriate, psychometrically sound measures (American Psychiatric Association, 2013). Deficits in adaptive functioning have to be evident across one or more domains (American Psychiatric Association, 2013).

The DSM-5 refers to adaptive functioning as “how well a person meets community standards of personal independence and social responsibility, in comparison to others of similar age and sociocultural background” (American Psychiatric Association, 2013, p.37). The term adaptive functioning first appeared in the 1961 American Association on Mental Deficiency (AAMD) manual (Heber, as cited in Schalock, 2011). It was a term that attempted to combine deficits in maturation, learning and social adjustments (Schalock, 2011). The DSM-5 uses classifying terms [mild, moderate, severe and profound] to help describe the impact of the disorder on the individual as they operate in the world and the type of support and service which may be required (American Psychiatric Association, 2013). The onset of the disorder has to occur within the developmental period (before the age of 18) for a diagnosis to be made and must have a lifelong course (American Psychiatric Association, 2013).

In the previous edition, the DSM-IV-TR, ID was referred to by the term Mental Retardation (American Psychiatric Association, 2000). The disorder is described as being characterised by “significant sub-average intellectual functioning defined as the individual having an intelligence quotient (IQ) score of 70 plus or minus 5 points” (American Psychiatric Association, 2000, p.41). This significant sub-average intelligence also has to be “accompanied by significant limitations in adaptive functioning” (American Psychiatric Association, 2000, p.41). Adaptive functioning in the DSM-IV-TR involves significant limitations in at least two skill areas encompassing “communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety” (American Psychiatric Association, 2000, p.41). The

differences between DSM-5 and DSM-IV-TR and the interpretation of adaptive functioning deficits are important to consider, as a deficit as outlined by the DSM-5 must occur across one whole domain, in other words, as a unified difficulty (American Psychiatric Association, 2013), whereas in the DSM-IV-TR difficulties can occur in two of the skill areas listed above, which may or may represent unified difficulties in a domain (American Psychiatric Association, 2000). This could potentially mean individuals who were considered to have an ID under the DSM-IV-TR may no longer meet criteria under the DSM-5. As with the DSM-5, the DSM-IV-TR outlines that the onset of the disorder must occur before the age of 18.

The ICD-10, as with the DSM-IV-TR, refers to the disorder as Mental Retardation (World Health Organisation, 1992). It should be noted however, that the World Health Organisation (WHO) have noted their intent to change the terms ‘retardation’ and ‘retarded’ in the ICD-11 (World Health Organisation, 1996). Mental retardation is referred to by the WHO as “a condition of arrested or incomplete development of the mind” (World Health Organisation, 1996, p.1). “It is characterised by impairment of skills manifested in the developmental period such as cognitive, language, motor and social skills” (World Health Organisation, 1996, p.1). The ICD-10 outlines that the assessment of intelligence “should be based on whatever information is available including: clinical findings, adaptive behaviour (judged in relation to the individual’s cultural background), and psychometric test performance” (World Health Organisation, 1996, p.1).

A key difference between the DSM-IV-TR, ICD-10, and DSM-5 involves the classification terms mild, moderate, severe and profound and how these are assigned. As mentioned above, the DSM-5 uses these terms to describe the impact of the disorder on the individual and their level of need, whereas the DSM-IV-TR and ICD-10 assign these on the basis of an individual’s IQ score: mild is assigned if the person’s IQ falls between 50-55 to approximately 70, moderate 35-40 to 50-55, severe 20-25 to 35-40 and profound below 20-

25. These differences are important to consider as, depending on the diagnostic manual a health practitioner uses, the classification of an individual with ID can vary significantly.

An alternate definition is provided by Thomson et al. (2009): “ID is understood as a multidimensional state of human functioning in relation to environmental demands” (p.135).

Critically, ID as a disorder falls among the top 20 health disorders in the world in terms of difficulties faced by the individual with ID, those supporting them and cost (Einfield, Ellis & Emerson, 2011). Individuals with ID represent approximately 1% (28,900) of the NZ population (Perkins, 2007). Within NZ, individuals with an ID are four times more likely to be hospitalised for avoidable conditions and also have similar rates of utilisation of primary health facilities (Ministry of Health. 2013). Therefore, it is important to look at how health practitioners conceptualise and address these problems.

Research has consistently suggested that individuals with ID have unmet health needs (Mirfin-Veitch & Paris, 2013). The NZ Ministry of Health (2013) also state individuals with an ID “do not receive health services frequently enough” (p.iv) in light of their needs and “that the quality of health services they do receive is often inadequate” (p.iv). By having unmet health needs, individuals with an ID may experience a greater severity of mental health difficulties than if these health needs were addressed sooner and/or with better service provision (Hughes, 2009).

## **1.2 History of ID Care and Treatment**

People with ID have existed in all societies throughout recorded history (Bray, 2003). As with all human characteristics, intellectual and adaptive functioning vary across the total population. Individuals diagnosed with an ID are those who are deemed, according to the measurements and tools used to assess intellectual capacity and adaptive functioning, to fall outside that which is considered the norm of society. However, the way in which society has viewed individuals with IDs has varied greatly over time (Bray, 2003). The construct of what

a disability is and what it means to have a disability has also shifted over time (Schalock, 2011; Milner, Gates, Mirfin-Veitch & Stewart, 2008). As such, this has impacted upon the assessment and treatment of individuals with an ID (Schalock, 2011; Milner et al, 2008).

Schalock (2011) describes four approaches that have, over time, defined how individuals with an ID have been classified. These include social, clinical, intellectual and dual-criterion (Schalock, 2011). Individuals with an ID were initially defined or identified due to their social behaviour and failure to adapt/fit in appropriately according to social expectations (Schalock, 2011). With the worldwide shift and influence of the ‘medical model’, defining an individual with an ID became reliant on a person’s symptom complex and “clinical syndrome” (Schalock, 2011, p. 225). This ‘clinical’ approach centered on individuals with an ID being very different from the ‘norm’ and therefore problematic (Milner et al, 2008). Whilst it did not entirely negate the social approach, the focus fell much more on heredity, pathology and the need for segregation (Schalock, 2011). The intellectual approach that followed deemed intellectual functioning the main criterion for defining ID (Schalock, 2011); this was in light of the rise of the mental testing movement (Schalock, 2011). The dual-criterion approach operating now involves the attempted combination of both intellectual and social criteria to categorise individuals (Schalock, 2011).

Within NZ and prior to Pākehā colonisation, traditional Māori ensured individuals with an ID were embedded within society (Milner et al, 2008). Māori differed in their understanding of disabled whanau, emphasising whanaungatanga (family relationships) as the cornerstone of identity (Milner et al, 2008). The emphasis upon shared familial connection and an understanding of wellbeing that included elements of *tikanga* (custom and obligation), *manaaki* (respect, support and hospitality) and the ability to contribute to *īwi* and whanau, positioned Māori with an ID to a social position within their own community (Milner et al,

2008). This provided a specific identity for all members of society, without differentiation based on an individual's intellectual functioning capacity.

The 'clinical' approach Schalock (2011) describes was dominant in many countries, including NZ during parts of the 19<sup>th</sup> and 20<sup>th</sup> centuries. This was reflected in state policy, which deemed control and containment of individuals with ID as an appropriate response to the "problems" created by ID (Milner et al, 2008, p.6). Institutional care was proposed as "protective shelter for the feeble-minded from the moral dangers of society" (Milner et al, 2008, p. 6). It was also framed as liberating people from inappropriate workhouses, asylums and goals and delivering them into the safer care of the emergency medical practices of surveillance, classification and treatment (Milner et al, 2008). This had the effect of shifting individuals with an ID away from the community and into isolated facilities, separating both population groups away from each other and limiting interactions, experiences and understanding (Milner et al, 2008; Schalock, 2011).

During the early part of the 20<sup>th</sup> century, the NZ government passed the Mental Defectives Act, which made it illegal for families to care for a person with an ID within a their home, further driving the wedge between community inclusion, integration and care (Milner et al, 2008). By 1928 this was altered and was no longer illegal (Milner et al, 2008). However, families were required to register their 'mentally defective' children with the Eugenics Board (Milner et al, 2008). From the 1920s, pre-existing institutions were transformed into hospitals (psychopaedic hospitals) as the medical model became increasingly dominant (Milner et al, 2008). If families decided to keep a family member with an ID at home, they received no aid from the state (Milner et al, 2008). For those who did choose this option not only were there financial implications, but they also faced considerable prejudice and rejection (Milner et al, 2008). A self-advocate and previous resident of The Kimberley Centre (psychopaedic hospital) in NZ, Robert Martin, remembers, "When I was

able to look back on what happened, I started to understand how my disability had affected everyone in my family. They did not have the support of family and friends. No one was there to help them understand my disability. Their friends withdrew. Even their family stopped visiting. They became a ‘disability family’. It has taken me a long time to understand that,” (Milner et al, 2008, p.7).

In NZ the deinstitutionalisation process (in line with international trends) began to gather momentum during the 1970s and 1980s (Milner et al, 2008), reflective of considerable shifts in western societal thinking at the time (Milner et al, 2008). This included normalisation for all members of society, irrespective of their intellectual capacity (Milner et al, 2008; Chowdhury & Benson, 2011). Wolfensberger and Tullman (1982) state that “normalization implies, as much as possible, the use of culturally valued means in order to enable, establish, and/or maintain valued social roles for people” (p.131). It also included the recognition of the impact of deprivation of maternal care and institutional care as demonstrated by researchers such as Bowlby and Baritone (cited in Milner et al, 2008). There was also increasing recognition of the moral and ethical obligations of society to look after and care for vulnerable individuals and groups (Milner et al, 2008). Additionally, while opinions have varied as to whether the cost of institutional or community care is higher (Chowdhury & Benson, 2011), it is likely, in line with North American findings (Campbell & Heal, 1995; Stancliffe & Lakin, 1998) that the deinstitutionalisation movement in part was motivated by the proposed reduced cost of running community care residences compared to institutionalised care.

With the movement to community settings, considerable changes occurred not only for individuals with an ID and their families, but also those involved with their care (Milner et al, 2008; Dovey & Webb, 2000). A study carried out by Nøttestad and Linaker (1999) in Norway examined mental health and behavioural difficulties of individuals with ID whilst

living in institutionalised care and following deinstitutionalisation. The study demonstrated that whilst diagnoses of mental health conditions did not significantly alter, the identification of behavioural difficulties significantly increased following deinstitutionalisation (Nøttestad & Linaker, 1999). In the institutions, care workers and health practitioners (e.g. Nurses, Clinical Psychologists, Psychiatrists, Occupational Therapists) worked together in a team-like environment with centrally located expertise. The movement to the community resulted in the decentralisation of expertise (Milner et al, 2008; Dovey & Webb, 2000). This posed new challenges for health practitioners, particularly if the availability of expertise was limited. Nøttestad and Linaker's (1999) study also indicated that individuals with an ID were much less likely to have regular mental health reviews with Psychiatrists or Psychologists following their move to the community. Despite the challenges that resulted from the deinstitutionalisation process, at the time it was deemed intellectual capacity was not a valid reason for isolating a section of the population from the rest of society (Milner et al, 2008).

One challenge resulting from deinstitutionalisation involved how to achieve effective community integration and the potential impact on the individual if this was not achieved. Whilst on a political and societal level there were significant shifts in attitudes regarding persons with an ID having a place in society, there were still significant attitudinal barriers that impeded effective community integration (Bray & Gates, 2003). O'Brien and Lyle O'Brien (1995) described people who were in communities without belonging to communities as an outcome for many individuals with ID following deinstitutionalisation.

O'Brien (1989) outlines five core valued human experiences for all people in society, including those with an ID. These include growing in relationships, contributing their skills and attributes, making independent choices, having dignity through a valued social role, and sharing ordinary places and activities in the community (O'Brien, 1989). O'Brien and Lyle O'Brien (1995) also suggest that for effective community integration there is a need for a

mutually respected and valued identity and social role, with recognition of the contribution that a person brings with their role. In contrast Bray and Gates (2003) pose the idea that individuals with ID may be viewed as having few roles and that these may be perceived as roles of dependency and lacking community contribution. Chaplin et al. (2010) discuss other factors that are important to consider within a community setting for individuals with ID as quality of life, social inclusion and types of residence. They also outline that these factors form part of a complicated two-way relationship with an individual's mental health.

### **1.3 Co-Morbid Mental Disorders**

A co-morbid mental disorder is another mental disorder that a person experiences in addition to having an ID (Mohr, Curran, Coutts & Dennis, 2002a). Individuals with an ID are at a highly increased risk of developing additional co-morbid mental disorder/s because of risk factors such as deficits in verbal and non-verbal reasoning, communication, processing, planning, memory and emotional regulation (Werner & Stawski, 2012; Mohr, Phillips, Curran & Rymill, 2002b; Hughes, 2009). It is estimated that individuals with IDs are up to 40% more likely to experience a co-morbid mental disorder than those of the general population (Cooper, Morrison & Melville, 2007; Deb, Thomas & Bright, 2001). Within NZ, individuals with an ID are three times as likely as the general population to receive care or treatment for any mental health disorder (Ministry of Health, 2011). More specifically, they are twice as likely to receive care or treatment for a mood disorder and seventeen times as likely to receive care or treatment for a psychotic disorder (Ministry of Health, 2011). The isolation and lack of appropriate support that many individuals with ID have experienced whilst living in the community as outlined by O'Brien and Lyle O'Brien (1995) may exacerbate any underlying mental health conditions the individual is experiencing.



#### **1.4 Difficulties in Diagnosing Co-morbid Disorders in the ID Population**

Given the factors and statistics mentioned above, there is a need to ensure that people with an ID are provided with comprehensive and appropriate mental health diagnosis and care (Allen, Lowe, Matthews & Anness, 2012; Hughes, 2009). Hughes (2009) argues that the right of individuals to have a healthy life and access to health services within NZ is captured by the United Nations (1948) in their document ‘Universal Declaration of Human Rights’. Hughes (2009) suggests that the document underpins NZ’s health and disability system. Article 25, point 1 in particular is of relevance to this, stating “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control” (United Nations, 1948). Yet research suggests that many health practitioners tasked with diagnosing and providing guidance as to the appropriate care for individuals with an ID feel unprepared, undertrained and overwhelmed when faced with these tasks (Dovey & Webb, 2000; Myrbakk & von Tetzchner, 2008; Werner & Stawski, 2012). Furthermore, Mirfin-Veitch and Paris (2013) describe a lack of knowledge by health professionals working with the ID population as an operational barrier to effective health service provision.

The deinstitutionalisation process poses a challenge to the health system in terms of ensuring that the mental health needs of those with an ID are attended to by health practitioners with suitable expertise and/or training (Dovey & Webb, 2000; Nøttestad & Linaker, 1999). Dovey & Webb (2000) explored general practitioners’ (GP) experiences, expectations and views with regard to this shift and the impact on their practice. They found that many recognised it was their role to care for individuals with an ID now residing in the community, yet they did not feel adequately trained to do so. The NZ Ministry of Health

(2013) have identified that this continues to pose a problem within NZ, with many GPs and other health practitioners seeing only a few people with an ID (as opposed to specialised services) and having limited training opportunities to prepare them to work with individuals with an ID (Ministry of Health, 2013).

It is increasingly recognised that it is crucial for accurate diagnosis to be made in individuals with an ID, as incorrect diagnosis can lead to inappropriate and ineffective mental health care (Health and Disability Commissioner, 1994; Moss, 2012). Accurate diagnosis helps to ensure access to adequate and appropriate health care and services, as per the individual's rights (Health and Disability Commissioner, 1994; Ministry of Health, 2012).

The initial health care and treatment provision of individuals with ID within NZ is usually delivered via primary health care providers (Ministry of Health, 2013; Dowell, Garrett, Collings, McBain, McKinlay, Stanley, 2009). The NZ Ministry of Health (2004) outlines that primary health organisations are key providers of mental health services and have responsibilities, for example, to know their enrolled populations' needs, understand the way in which mental health services are delivered by providers and understand the links with other service providers, assess the fit of their current services with the needs of their enrolled population and their practitioners, identify opportunities for aligning current services to be more effective in achieving improved mental health, and to decide what additional services will be necessary for an even greater improvement in mental health outcomes in the long term.

Since 2004 the NZ Ministry of Health has established Primary Mental Health Initiatives (PMHI) in order to increase funding for service delivery and infrastructure of mental health service provision in the primary health sector (Dowell et al, 2009). The Ministry of Health (2015) recommends that the primary health sector should, for all individuals, regardless of their IQ, adopt a stepped care approach to mental health service

provision. The aim of adopting this model according to the Ministry of Health (2015), is to provide patients with the most effective health care at the lowest cost. Secondary care or other specialists are engaged if required (Ministry of Health, 2013). Secondary and tertiary care services have also been required by the Ministry to reduce waiting list times as outlined in the Mental Health and Addiction Service Development Plan 2012-2017 (Ministry of Health, 2012). The movement through different levels of service provision is often referred to as a care pathway (Best Practice Advocacy Centre NZ, 2012).

Despite adopting this stepped care approach, the NZ Ministry of Health (2013) has identified that ‘primary care providers are likely to report they have received little information on treating people with ID while they were in training’. A survey of 137 GPs in the South Island of NZ examining their experience of and attitudes towards caring for individuals with an ID also supported this perspective, with many health practitioners reporting that they felt unprepared due to a lack of specific training in working with individuals with ID (Dovey & Webb, 2000).

If primary health care providers feel underprepared and ill equipped to provide services to individuals with an ID and co-morbid mental health disorders, this is likely to increase referrals to secondary care and specialist services (Torr, 2013). Yet secondary and specialist services have their own time and resource pressures, with research indicating that many health practitioners believe the ID population to be underserved, with inadequate provision of services (Pruijssers, van Meijel, Nijssen & van Achterberg, 2014; Edwards, Lennox & White, 2007; Jess et al, 2008, Mohr et al, 2002a; Dovey & Webb, 2000; Torr, 2013). Incorrect referral to these services in turn will only add to these time and resource pressures (Dovey & Webb, 2000). These factors may inadvertently involve the care pathways of health services being misused, with individuals being fast-tracked through the system to

secondary and tertiary services due to the difficulties that health practitioners at the primary level are experiencing (Best Practice Advocacy Centre NZ, 2012).

Alongside a lack of sufficient expertise, confidence and adequate service provision for the ID population, it has been argued that these factors are compounded by a general lack of interest from health practitioners to work with the ID population (Edwards et al, 2007; Torr, 2013). Kuehn (2003), a Psychiatrist working in this area, summarised these difficulties by saying:

“There is pathetically little interest in serving this special population, particularly among our leaders – the chairs of departments of psychiatry and mental health residency directors in medical schools” (p.911).

He also stated “I find that many Psychiatrists believe that working with this population would be ungratifying and frustrating because of their perception that these individuals are nonverbal, have severe behavioural problems, or are hopeless” (p.911).

This sentiment does not appear to be unique to NZ. For example, Edwards et al (2007) described that whilst the majority of Queensland Psychiatrists are actively treating adults with an ID, 43% were reluctant to treat this population. Furthermore, Bell and Williamson (2002) examined the number of articles related to the ID population in American journal *Psychiatric Services* between 1950 and 1999 and found that only 0.8% of articles published during this time related to the ID population, with all being published during the 1950's.

It has been argued that some of the difficulties associated with the correct diagnosis of co-morbid mental health disorders in individuals with ID involves the lack of clarity regarding role definition (Michael, 2008), i.e., whose job it is (in terms of mental health service providers and health practitioners) to assess and treat the ID population. Within NZ

(as with many other western nations) there is considerable debate as to which services and providers are responsible for which aspect of care (Dovey & Webb, 2000). Through prolonged discussions, movement of individuals and lack of responsibility in providing services, the risk of the individual (who is already part of a vulnerable group) not receiving adequate service provision and ‘slipping through the net’ is increased (Dovey & Webb, 2000; Iacono et al, 2003). McIntyre (2011) identifies the need for developing more integrated systems of care across, and with increased collaboration between, professionals, disciplines and services to ensure appropriate care and treatment of individuals with ID and co-morbid mental health disorders. Essentially, McIntyre (2011) calls for a more transparent and pragmatic care pathway.

One of the challenges that individuals with an ID and co-morbid mental health disorder face is that these disorders often have an atypical presentation when experienced by an individual with an ID (Mohr, Tonge, & Einfeld, 2005; Edwards et al, 2007; Langlois & Martin, 2008; Spindel, 2011; Bouras et al, 2004). This makes it difficult for health practitioners to rely on the criteria that would typically be used to diagnose a mental health disorder, such as the DSM-5, DSM-IV-TR or ICD-10 which are heavily reliant on the inclusion of verbal taxonomies. The intellectual limitations, potential communication restrictions (in particular, verbal) both in terms of receptive and expressive, and physiological variations and their impact on individuals with an ID may all potentially influence the accuracy of assessment and diagnosis of mental health disorders (Werner & Stawski, 2012). These diagnostic systems, therefore, hold an inherent assumption that health practitioners will hold the skills necessary to adapt to and account for the unique attributes and limitations of an individual with an ID, whilst also ensuring accuracy of diagnosis.

The NZ Ministry of Health (2013) acknowledges the difficulty that communication poses in ensuring adequate care for individuals with an ID. In a recent publication examining

the provision of health care for individuals with ID, the Ministry stated “communication between people with ID and health care providers is often problematic for both parties” (Ministry of Health, 2013, p.iv). They acknowledged that this contributes to the disparity of health provision and outcomes for those with an ID as compared to the general population (Ministry of Health, 2013). In addition, they report that professionals in both primary and secondary care either ‘(do) not listen to family and/or support workers who have too many expectations of them (for example, around their caring role), while not consulting the people with ID themselves’ (Ministry of Health, 2013, p.v).

The DSM-5, as with previous editions of the DSM (and other international versions of diagnosis manuals, such as the ICD-10), relies heavily on verbal communication (on the part of the individual being assessed) to ascertain whether an individual meets the diagnostic criteria to receive a diagnosis of a particular disorder (American Psychiatric Association, 2013; Moss, 2012). Given the potential verbal and communication limitations of individuals with ID, the question remains how to account for and adjust to these difficulties (Moss, 2012). A number of tools and assessment schedules have been developed in response to these recognised difficulties which aim to aid health practitioners in correctly diagnosing individuals who are experiencing a mental health difficulty alongside having an ID (Clarke, 2003; Felstrom, Mulryan, Reidy, Staines, & Hillery, 2005; Moss, 2012; Myrbakk & von Tetzchner, 2008). The most commonly researched tools for measuring general psychopathology in persons with ID have been subjected to a meta-analysis by Matson, Belver, Hattier, and Matson (2012).

Despite there being a number of ID-specific tools, there are several issues and limitations. The most commonly used tools and their psychometric properties are described below. The Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) checklist was developed as a screening tool to assist care staff identify likely

mental health concerns and make informed referrals (Pavilion Publishing, 2010). The PAS-ADD checklist has been found to be easy to use and sensitive, although the question remains as to its specificity (Taylor, Hatton, Dixon, & Douglas, 2004). In another study Moss, et al (cited in Matson et al, 2012) found internal consistency to be good, but inter-rater reliability to be low. Zeilinger, Weber and Haveman (2011) also reported very good internal consistency and test-retest reliability. Perez-Achiaga, Nelson and Hassiotis (2009) found the PAS-ADD checklist to have robust psychometric properties, with good validity in regard to depressive symptoms.

The Mini PAS-ADD is an assessment schedule that takes the form of either an informant interview or the gathering of information by a trained staff member who has knowledge of the individual (Prosser et al, 1998). Unlike the PAS-ADD checklist, the Mini PAS-ADD can be used to aid in diagnosis in conjunction with health practitioners' interpretation (Prosser et al, 1998). Studies have indicated acceptable validity for the Mini PAS-ADD and generally acceptable reliability (Prosser et al, 1998). In a study conducted by Myrbakk and von Tetzchner (2008), results for the psychosis and obsessive-compulsive scales indicated a much lower level of internal consistency than was revealed in the Prosser et al (1998) study. Its reliability appears to vary depending on the experience level of the health practitioner/s, illustrating the importance of adequate training in the use of the measure (Prosser et al, 1998). In addition, the validity of the checklist has been questioned as a result of the schedule not encompassing every disorder (Prosser et al, 1998).

The PAS-ADD clinical interview, for use with an individual with ID, is described as the most comprehensive of all PAS-ADD tools (Pavilion Publishing, 2010), although it can only be used for individuals that can verbally contribute to the interview in some capacity (Pavilion Publishing, 2010). Research has suggested that individuals require a mean IQ score of 39.2 to respond adequately to the clinical interview (Patel, Goldberg, & Moss, 1993).

However, Patel et al (1993) point out that an individual's measured IQ is not always predictive of their verbal abilities and that in some instances individuals with low IQ were able to participate in a good clinical interview. The PAS-ADD clinical interview provides a number of diagnoses but does not account for all psychiatric diagnoses (Pavilion Publishing, 2010). It is the only PAS-ADD tool that fully covers psychotic illnesses in depth (Pavilion Publishing, 2010), and the validity and reliability of the PAS-ADD clinical interview appear adequate to justify its use (Moss, Prosser, and Goldberg, 1996; Moss et al, 1997). It should be noted however that Moss, Prosser, and Goldberg (1996) found that agreement between participant and informant data was poor, with only 40.7% of instances of psychopathology being identified by both.

The Diagnostic Assessment Schedule for Severely Handicapped-II (DASH-II) was developed in 1995 and is another widely used tool (Matson et al, 2012; Paclawskyj, Matson, Bamburg, & Baglio, 1997). It was designed for use with individuals with more severe ID (Paclawskyj et al, 1997) and measures 13 mental health disorders that are derived from the DSM-IV-TR (Matson et al, 2012). The tool involves caregivers rating the frequency, duration and severity of the symptoms (Myrbakk & von Tetzchner, 2008). Good inter-rater reliability, as well as good internal consistency was found across a number of studies (Matson et al, 2012). It also has a good convergent validity with the Aberrant Behaviour Checklist (Paclawskyj et al 1997; Sturmey, Matson, & Lott, 2004). A number of other studies have indicated good internal consistency on a number of subscales, such as the mania subscale, sleep subscale and schizophrenia subscale (Matson et al, 2012).

The Reiss Screen for Maladaptive Behaviour is another widely used scale for measuring psychopathology in adults with ID (Matson et al, 2012). The screen is completed by caregivers who are asked to rate the extent to which 38 symptoms are no problem, a problem, or a major problem in the ID individual's life (IDS Publishing, 2011). The language



used is non-technical and is supported by a number of concrete examples (IDS Publishing, 2011). It has been found to have good face validity, as well as good reliability for the various scales by a number of research articles (Matson et al, 2012). Perez-Achiaga et al (2009) also state that the Reiss scale has robust psychometric properties and is well validated with regard to screening depressive symptoms. However, it has at times been criticised for not having a more comprehensive set of items (Matson et al, 2012).

The Psychopathology Instrument for Mentally Retarded Adults (PIMRA) is a 56 item test developed and based on the DSM-III, with both self-report and informant report versions available (Matson et al, 2012). It was one of the first scales developed specifically for use with the ID population and is still widely used today (Matson et al, 2012). It has been found to have good internal consistency as well as test-retest reliability and good overall validity (Matson et al, 2012). Matson et al (2012) discuss a number of other, less frequently used and researched general scales in their meta-analysis. These include the Adult Behaviour Checklist, Assessment for Dual Diagnosis, Brief Symptom Inventory, Clinical Global Impression Scales, General Assessment of Functioning, Psychopathology Checklist for Adults with Adults with Intellectual Disability, and the Prout-Stromer Assessment System and Psychopathology Inventory for Mentally Retarded Adults.

There are other tools that have not been mentioned in this thesis due to the fact they are designed specifically for use with children with an ID. Worthy of mention, however, is that the Developmental Behaviour Checklist, specifically designed for use with children and one of the most frequently used and researched tools, has been adapted for use with adults by Mohr et al (2005) and called the Developmental Behaviour Checklist for Adults. However, there appears to be limited research available on this adult version.

Other tools have been designed for use with ID individuals for specific disorders. The Glasgow Depression Scale for people with a Learning Disability (GDS-LD) has been

specifically developed for use with individuals with ID (Ailey, 2009). Ailey (2009) compared the GDS-LD with the Beck Depression Inventory II (BDI-II) (designed for use with the general population) for individuals with ID. Whilst the findings were adequate and similar for both tools, the GDS-LD had better item reliability than the BDI-II for the ID population (Ailey, 2009). Ailey (2009) states that the GDS-LD more clearly separates participants in terms of levels of depression and items as reflecting different levels of the construct of depression. She concludes that the GDS-LD is a more useful tool than the BDI-II for screening individuals with ID and depression (Ailey, 2009). Perez-Achiaga et al (2009) suggest that the GDS-LD has promising results in terms of its psychometric properties but requires further validation against well-established diagnostic criteria for depressive disorders. Other tools and screens to measure depression in individuals with ID have been developed (Perez-Achiaga et al, 2009), however these have undergone less research and are less widely used than the GDS-LD (Perez-Achiaga et al, 2009). These tools include the Self Report Depression Questionnaire, the Mood, Interest, and Pleasure Questionnaire, the Mental Retardation Depression Scale, the Depression and Mood Scale, and the Marston Checklist.

Anxiety specific tools for use with the ID population have also been widely researched. In their meta-analysis, Hermans, van der Pas and Evenhuis (2011) found a number of widely-used anxiety specific tools with good psychometric properties. The Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID) was developed as a self-report measure (Hermans et al, 2011). It has strong psychometric properties with good test-retest reliability and internal consistency (Hermans et al, 2011). It is able to discriminate anxious from non-anxious individuals well and is reasonably correlated with the Beck Anxiety Inventory – II (BAI-II) (Hermans et al, 2011).

The general anxiety scale of the Anxiety, Depression and Mood Scale is an informant measure (Hermans et al, 2011). It appears to have good reliability, except for inter-rater

reliability, which was poor (Hermans et al, 2011). Other measures of anxiety in people with ID are available but appear to possess less sound psychometric properties. These include the Fear Survey for Adults with Mental Retardation and the Mood and Anxiety Semi-Structured Interview (Hermans et al, 2011).

The Diagnostic Criteria for use with adults with Learning Disabilities (DC-LD) was developed in 2001 to assist health practitioners diagnose psychiatric disorders in individuals with ID (Einfeld, 2003; Felstrom et al, 2005; Cooper, Melville & Einfeld, 2003). This is a diagnostic system as opposed to a specific tool or screen. The DC-LD was developed out of the recognition that more general psychiatric classification systems (such as the ICD-10 and DSM-IV-TR) were not always suitable for use with individuals with ID (Cooper, Melville & Einfeld, 2003; Einfeld, 2003). The DC-LD is based on the format of the ICD-10 with modified criteria on the basis of how disorders present in the ID population (Einfeld, 2003). In a study conducted by Felstrom et al (2005) which examined the applicability of the DC-LD for use with individuals with ID, it was found that the DC-LD was a useful tool for health practitioners. However, for individuals with moderate to severe ID, diagnostic problems were still apparent (Felstrom et al, 2005).

As with the DC-LD, the Diagnostic Manual-Intellectual Disability (DM-ID) test was developed out of the recognition that general psychiatric diagnostic systems are not always appropriate for use with individuals with ID (Ninivaggi, 2008). Similar to the DC-LD, the DM-ID is a diagnostic system as opposed to a specific psychometric tool or screen. The DM-ID was designed as a complementary system to the DSM-IV-TR; diagnostic criteria are described and modified in light of the diagnostic categories outlined by the DSM-IV-TR (Ninivaggi, 2008). These modifications were created on the basis of expert consensus (Kastner & Walsh, 2009), though the authors acknowledge that there is a lack of scientific evidence behind these modifications (Kastner & Walsh, 2009). More research is therefore

required to ascertain the applicability of the modified criteria in the DM-ID (Kastner & Walsh, 2009).

Despite evidence suggesting these tools are likely to aid in assisting health practitioners establish an accurate diagnosis, it remains to be seen whether these tools are used effectively or are indeed even known about, particularly among health practitioners who do not work in specialist ID services. Ironically, it is the health practitioners working in general practice, isolated from specialist services, who would likely gain the most positive benefits from being aware of and using these tools. Furthermore, whilst there are currently tools and instruments available to assist with the accurate diagnosis of co-morbid disorders, these are still not ideal and further refinement of the measurement of mental health disorders for the ID population is necessary (McIntyre, 2011; Mohr et al, 2005).

Another consideration in the difficulties associated with communication relates to the reliance of information communicated by family members or the carers of individuals with ID. Research has indicated (particularly in the case of individuals who cannot communicate verbally) that health practitioners rely heavily on support workers' and family members' reports of the individual to gain an understanding and picture of the difficulties experienced (Ministry of Health, 2013). In many cases, however, it appears that the support workers and/or family members may be unaware, or not fully aware, of health issues the individual with ID is experiencing, leading to these not being reported or being misreported (Krahn, Hammond & Turner, 2006). In other situations, an overreliance on support workers or family members for information has resulted in the individual with an ID being ignored or not being given enough time to process a question and respond themselves (Ministry of Health, 2013). Also, the various avenues through which the individual with an ID may be able to communicate effectively may not have been explored in enough detail and depth (Ministry of Health, 2013). Iacono et al (2003) found that many GPs hold concerns about the ability of the

individual with an ID to communicate their difficulties as well as their ability to understand and follow management plans.

Within NZ, the Ministry of Health (2013) has identified that at least one reason for the health inequalities experienced by individuals with IDs compared to the general population arises from “diagnostic overshadowing” (Ministry of Health, 2013, p.7). This is described as the process “whereby symptoms are attributed to a person’s disability rather than to a separate condition (particularly for mental health conditions)” (Ministry of Health, 2013, p.iv). Taua and Farrow (2009) outline that up until the mid-1950s, psychiatric orthodoxy suggested individuals could not have both a mental illness and ID. Matson and Scior (2004) describe overshadowing as involving the tendency of health practitioners to overlook symptoms of mental health problems and instead attribute them as part of having an ID, therefore discounting evidence to the contrary. Perkins (2007) also discussed the difficulties in diagnosing people who have an ID with mental health disorders, reflecting on the complexities of deciphering the cause of dysfunctional behaviour and extreme emotional expression. This is also reflective of international research that indicates many health practitioners are unclear whether symptoms and difficulties displayed by the individual are due to a mental health disorder, the ID in and of itself, or maladaptive behaviour (Jopp & Keys, 2001; Krahn et al, 2006; McIntyre, 2011).

Another factor that complicates the accurate diagnosis of co-morbid mental health disorders for individuals with an ID is challenging behaviour (Perkins, 2007; McIntyre, 2011). The challenging behaviour that an individual displays may or may not be a symptom of a mental health issue. For example, the behaviour may form part of an atypical presentation of the mental health disorder. i.e., an individual who has an ID and communication difficulties may be experiencing a social anxiety disorder. A symptom of this disorder may be that they scream continuously when a person they do not know comes into

their house. Carers who are not formally trained in understanding communication issues may mistakenly interpret such screaming as being purely behavioural rather than entertaining the possibility of it being a symptom of a deeper mental health problem.

According to Deb et al (2001), individuals with an ID are more likely to exhibit serious behaviour disorders or challenging behaviours in and of themselves compared to those without an ID. This further complicates the already unclear waters as to the attribution of these behavioural difficulties. This poses the question as to whether the behaviour is due to affect, individual style or indicative of a formal mental health condition.

There is considerable health practitioner debate as to how these difficulties should be formulated and addressed (McIntyre, 2011). If this is the case, it raises the question of how to differentiate between mental health difficulties and challenging behaviour.

### **1.5 Summary and Purpose of the Current Study**

As has been outlined above, individuals with ID are predisposed to a number of difficulties that those without an ID are much less likely to experience (Taylor et al, 2004). In particular, co-morbid mental health disorders are more likely to occur for individuals with ID (Werner & Stawski, 2012; Mohr et al, 2002b; Hughes, 2009). For example, in NZ psychotic disorders are more than seventeen times more likely to occur for a person with an ID (Ministry of Health, 2011).

Given the risk factors associated with mental health disorders, particularly in relation to a vulnerable population such as individuals with an ID, it is extremely important that health provision, diagnosis and treatment are accurate and appropriate. Yet in many cases health practitioners tasked with assessing and treating individuals with an ID who have co-morbid mental health conditions often feel underprepared, undertrained and ill equipped to provide such a service (Dovey & Webb, 2000; Myrbakk & von Tetzchner, 2008; Werner & Stawski, 2012).

In the past 20 years during the deinstitutionalisation process, an increased pressure on primary health care health practitioners, as well as secondary and tertiary health care practitioners has occurred. Many primary health practitioners may have little, if any, experience in working with this unique population. Ironically, there was more structured access to health care for ID individuals during the institution-era, for example institutions had ID-specific doctors and nurses. This poses challenges to obtaining the experience and confidence to work effectively with such individuals.

Research indicates that the majority of health practitioners (Psychiatrists, Psychologists and GPs) consider that the ID population does not receive adequate health provision for their mental health needs (Pruijssers et al, 2014; Edwards, Lennox & White, 2007; Jess, et al, 2008, Mohr et al, 2002a; Dovey & Webb, 2000). These authorities identify a lack of confidence, training and experience as factors which complicate appropriate service provision for individuals with ID (Dovey & Webb, 2000; Edwards et al, 2007; Iacono et al, 2003; Nøttestad & Linaker, 1999; Werner & Stawski, 2012).

The responsibility of different roles and services in working with the ID population is also widely debated and research has demonstrated that this has led to a lack of communication and responsibility, with individuals often receiving insufficient and/or inadequate assessment and treatment (McIntyre, 2011). Attitudinal factors of general society, caregivers and health practitioners may also contribute to contextual situations that give rise to the development, maintenance and treatment of mental health disorders in individuals who have an ID (Edwards et al, 2007; O'Brien & Lyle O'Brien, 1995).

Given the difficulties of individual communication ability, individual insight, information sources, atypical presentations and access to appropriate health practitioners, it is understandable that the diagnosis and treatment of co-morbid mental health disorders in the ID population poses significant challenges. It is therefore important that research attempts to

gain a better understanding of these difficulties and how they may be overcome. No studies during the literature search for this current study yielded cross-profession views in regards to the difficulties experienced in assessing, diagnosing and treating co-morbid mental health difficulties for the ID population. In addition, whilst previous research examined difficulties experienced, very few examined the ways in which health practitioners have overcome and addressed these issues. As such, this study has two primary purposes. Firstly, it aims to draw on the experiences and difficulties that NZ health practitioners in various professions (including Psychiatrists, Clinical Psychologists and General Practitioners (GPs)) have experienced in assessing, diagnosing and treating co-morbid mental health disorders for individuals with ID. Secondly, the study aims to identify the ways in which these health practitioners have overcome or addressed the difficulties that they have experienced. It is hoped that this research will provide health practitioners who may potentially deal with similar issues in the future, with guidance in what issues they may encounter as well as how they may overcome these challenges.



## CHAPTER TWO – METHODOLOGY

### 2.1 Design

**Qualitative research.** The nature of this study involves examining individual health practitioner's perspectives and the evolution of adapted clinical practices in overcoming perceived shortcomings in diagnostic frameworks when diagnosing a mental health disorder in an individual with an ID. By using a qualitative approach it was hoped the research would gain access to rich and in-depth personal experiences and accounts of health practitioners working with individuals who have an ID and co-morbid psychiatric conditions (Bhati, Hoyt, & Huffman, 2014). Povee and Roberts (2014) describe qualitative research as providing a level of depth and context for human behaviour and responses in ways that quantitative approaches cannot. Quantitative approaches yield strong numerical data that in many cases are used to support or disconfirm a hypothesis (Newman & Benz, 1998), while qualitative approaches are generally more naturalistic and are used by researchers to observe and interpret 'realities' as they understand them from the data (Newman & Benz, 1998). Quantitative methodologies generally do not provide the same level of descriptive information as qualitative approaches. For this project it was important to gain in-depth information regarding the difficulties surrounding diagnosing co-morbid mental health issues for individuals with ID to fully understand the breadth and complexity of the area. In addition, this research was not designed with a specific hypothesis in mind but instead aimed to provide an overview and interpretation of how health practitioners perceive, assess and overcome the challenges associated with diagnosing mental health issues in individuals with ID.

**Online survey.** The research design for this project takes the form of a two-level design. An online survey was chosen as the first method of the data collection as it is a flexible (via email directly, through URL links or webpages), timely, convenient and non-

costly survey method (Evans & Mathur, 2005). Ramo, Hall and Prochaska (2011) further outline benefits of online surveys as having the ability to reach a broader group of participants, allowing greater inclusion of low incidence or 'hidden' populations, and reducing bias in response to sensitive, potentially stigmatising topics compared to other methods such as face-to-face interviewing. Online surveys have received some criticism in the past, for example for their potentially impersonal presentation, low response rates, perception of junk email and lack of representative sampling due to differences in familiarity with the internet and computer technology (Evans & Mathur, 2005). By providing a strong introduction to the survey in email invitations sent out, as well as distribution from various professional bodies, it was hoped that these difficulties could be overcome. In addition it was hoped the anonymous nature of the survey would encourage individuals who were perhaps less likely to feel confident or comfortable taking part in a face-to-face interview to contribute in a way that suited their needs.

**Focus groups.** The second data collection method used was a focus group. Focus groups encourage interaction between participants as well as with the moderator (Wilkinson, 1998; Morgan, 1996) and enable qualitative insights not only from individual participants but also within the context of the group's shared or collective understanding and interactions (Sheriff, Gugglberger, Hall, & Scholes, 2014; Stokes, & Bergin, 2006). This is a considerable difference between this and other group formats such as group interviews, which involve interviewing multiple participants simultaneously without examining the interaction between them (Sheriff et al, 2014). Focus groups can also be differentiated from other group methods, such as group discussions which tend to be less directed than focus groups, with participants largely deciding the structuring and choice of issues discussed (Sheriff et al, 2014). As such the qualities of focus groups include the ability of the researcher to facilitate and at times

direct group discussion, whilst also allowing natural interactions and shaping of topic areas by the participants (Sheriff et al, 2014).

Focus groups can be useful in pursuing interesting findings from large-scale surveys (Wilkinson, 1998), such as that used in the first step of this project. They can also add richness and depth to the data gathered in a way that quantitative methods are unable to (Wilkinson, 1998). According to Morgan (1996), focus groups are being increasingly utilised by researchers as a secondary stage following an initial survey in order to develop the content further. Given that this research aims to focus on the broad challenges health practitioners experience in diagnosing co-morbid mental health issues in individuals with ID and how they overcome these challenges, focus groups were chosen to enable the researcher to ensure a semi-structured environment of participant interaction.

**Individual interview.** Alongside the focus group, an individual interview was also conducted with a GP in the second stage of the data collection. Individual interviews allow researchers to shape questions, enabling a greater level of depth, context and at times flexibility than other methods of data gathering such as surveys or group information gathering designs (Stokes & Bergin, 2006). Stokes and Bergin (2006) also outline other advantages of individual interviews, including being able to build a close rapport and higher level of trust than other data gathering methods, which can help yield ‘better’ data, as well as the potential for more non-conforming information than may be possible to attain in a group environment. In addition, by being listened to and afforded anonymity, participants may feel a sense of empowerment (Stokes & Bergin, 2006). The face-to-face nature of an individual interview also allows the researcher advantages in being able to read social cues and adjust their questioning style accordingly, in a way that other methods such as phone interviews do not allow for (Opdenakker, 2006). Initially it was hoped that focus groups with GPs would take place to yield the various advantages of this method as outlined in the section above.

However, due to the low response rate during the online survey stage, it was concluded that conducting individual interviews for GPs was more likely to attract more participants as the researcher could attend the interview at a place convenient for the GP, affording potential participants a greater level of flexibility.

**Thematic analysis.** Thematic analysis was used throughout this project. Analysis was carried out on the data yielded through the online surveys, then directly shaped and contributed to the construction and direction of the focus group and questions in the individual interview. Thematic analysis is a qualitative approach used for identifying, analysing and reporting themes and patterns within data (Braun & Clarke, 2006). It is a reflective and ongoing process requiring the researcher to identify key themes in a data set (Braun & Clarke, 2006). It takes place through the use of coding.

Coding involves reading through the data as it is collected and identifying the key reoccurring patterns (themes) of data as interpreted by the reader (Davidson & Tolich, 2003; Braun & Clarke, 2006). It should be noted that key themes do not necessarily have to be those which occur most commonly, although this is often the case (Braun & Clarke, 2006). Instead, through examination and analysis of the data collected, key identified themes are dependent on the individual judgement of the researcher (Braun & Clarke, 2006). A central element of thematic analysis is that the codes can change and adjust as the analyst reads through the data (Braun & Clarke, 2006). This method therefore encompasses the practice of ongoing reflective dialogue and thought (Braun & Clarke, 2006).

Thematic analysis was selected over other qualitative analysis methods due to the aims of this project not specifically revolving around generating a theory of phenomena. A bottom-up approach such as used in this project involves data-oriented research and does not rely on the construction of an explanatory theory prior to the onset of the project (Haig, 2013).

Braun and Clark (2006) point out that despite best intentions, researchers are inevitably influenced by their own theoretical positions and values. In turn, these undoubtedly shape what is identified and focused on by the researcher (Braun & Clarke, 2006). Braun and Clarke (2006) point out that it is important for a researcher utilising thematic analysis to acknowledge and take responsibility for their own choices in deciding what to identify and focus on when thematically analysing data. There is debate within the literature as to whether multiple coders should be used to try and ensure reliability and validity (Hruschka et al, 2004). Braun and Clarke (2006) argue that engaging multiple coders can detract from the unique interpretation of the individual researcher and run the risk of diluting their findings.

According to Braun and Clarke (2006), the quality of the thematic analysis of a project is based on a number of key factors. These include following a robust process, applying a critically analytical eye to the data collected, and interpreting any data in light of what is already known about the issue(s), i.e., through past research (Braun & Clarke, 2006).

## **2.2 Measures**

**Online survey questionnaire.** A questionnaire was developed to elicit information from participants regarding a number of key topics. Questions were designed to elicit the following: demographic information, the health practitioners' personal experiences of challenges in diagnosing mental health issues in individuals with ID and how they overcome these challenges, and areas that have been outlined by previous research in the literature as problematic. These areas are explored in greater detail below. Within the questionnaire there was a mixture of closed-response items (e.g. Yes/No and Likert-type scale), six in total, and open-response items, 26 in total. Questions were designated closed-response type or open response type depending on the type of information being sought. In total the online survey consisted of 32 questions, the first asking the participant to consent to take the survey. Some of the other 31 questions were not coded (Table 1) due to being either a demographic

question, i.e. *What is your professional qualification?*, yes/no questions such as *Have you ever worked with an individual with an ID?*, or a Likert scale question such as *How much of your current position and experience involves working with individuals with ID?* See Appendix E for a full list of questions used in the online survey.

The first part of the survey consisted of questions relating to the health practitioner's qualification and their prior experience in working with individuals who have an ID alongside co-morbid mental health diagnoses. For example, *How much of your current position and experience involves working with individuals with an ID?*

1. *Extensive*
2. *A lot*
3. *Some*
4. *A little*
5. *Minimal*

These questions were posed to help guide the researcher to understand the links (if any) between a participant's experience in working with the population and the difficulties they identify. They were also aimed at revealing health practitioners' confidence in this type of work. This specific question was asked as there are potentially a large number of health practitioners with varied experience who may be involved in diagnosing mental health issues in individuals with ID.

Further questions included the type of information/tools the participant uses in dealing with cases, as well as their perspective on how useful/reliable these tools are. These questions were developed in light of the availability of ID-specific and general tools, and with regard to previous research that suggests some health practitioners experience difficulties in adjusting diagnostic criteria and framing it to suit their clients. The questions were also developed in light of research suggesting the under-utilisation of ID specific tools. For example, *What formal tools/systems do you use in developing a mental health/psychiatric diagnosis in individuals with an intellectual disability?*

This area is also linked to communication difficulties between clients and health practitioners, another area indicated in the literature as problematic. Some specific examples of how a health practitioner would take into account diagnostic manual's criteria such as the DSM-5 (with a focus of criteria involving the use of language/description) were posed. For example, *With regard to Generalised Anxiety Disorder, how would you determine if "The person finds it difficult to control their worry"?* The concept of worry is essentially an internal mental process and therefore the issue arises as to how to adapt for a person with deficits in cognitive processing and verbal expression. These questions were used to try and establish how health practitioners overcome potential deficits of individuals with an ID, considering the verbal criteria that are included in the DSM and ICD taxonomy.

In addition and in relation to the difficulties in overcoming communication problems between health practitioners and clients, practitioner reliance on third party informants (such as family, care-givers) was explored. This was indicated by prior research as being potentially problematic in ensuring the accuracy of diagnoses (Ministry of Health, 2013). For example, *If you rely on a third party for information such as a caregiver and/or a parent or family member, how do you ensure their response accuracy?*

Practical aspects of the job role/work environment that may potentially impact upon the diagnostic process (e.g. time constraints) were also explored. These were developed in light of prior research that suggested many health practitioners experience difficulties due to the constraints of their work environment and the systemic pressures that accompany it (Ministry of Health, 2013; Pruijssers, van Meijel, Nijssen & van Achterberg, 2014; Edwards, Lennox & White, 2007; Jess et al, 2008, Mohr et al, 2002a; Dovey & Webb, 2000; Torr, 2013). For example, *How much time do you generally have in order to undertake a full formal assessment in order to make a mental health/psychiatric diagnosis?*

**Focus group.** The semi-structured format of the focus group was shaped by the main themes identified (via thematic analysis) in the first stage of the research project (Wilkinson, 1998; Braun & Clarke, 2006; Morgan, 1996). By drawing on the main themes identified during the initial surveying stage, broad areas of questions were developed. These were also in view of the prior research in this area as discussed in the section above (Ministry of Health, 2013; Pruijssers, van Meijel, Nijssen & van Achterberg, 2014; Edwards, Lennox & White, 2007; Jess et al, 2008, Mohr et al, 2002a; Dovey & Webb, 2000; Torr, 2013). These were targeted at providing a more detailed and in-depth understanding of the core issues affecting health practitioners through the diagnostic process and how they address and overcome the identified issues. See Appendix L for a list of specific questions and broad areas of discussion used as prompts in the focus group.

Broad pre-planned areas of questions included challenges the health practitioners had experienced, how they overcame the challenges, societal perspectives of ID they had encountered, diagnostic systems (both specific and general), potential biases of third party informants, steps taken when unsure about diagnoses, and communication. Alongside these, discussion within the focus group shaped further questions posed by the researcher and the direction of conversation within the group. When the researcher believed that the conversation was moving away from the purpose of the focus group, questions were used to help reorientate conversation.

**Individual interview.** The structured format of the interview through specific questions was shaped by the main themes identified (via thematic analysis) in the first stage of the research project and in view of the prior research as discussed in the section above. In addition, questions were shaped by the online survey answers provided by GPs. These questions were targeted at providing a more detailed and in-depth understanding of the core issues affecting GPs and how they address and overcome the identified issues. This included



the amount of time and resources the GP has with an individual, confidence and experience in working the ID population, diagnostic tools available and used, challenges with specific disorders such as mood disorders, steps taken when encountering challenges and how the GP overcomes such challenges.

## 2.3 Procedure

### **Data collection.**

**Online survey.** Health practitioners were recruited from a number of sources, including a primary health organisation, NZ ID special interest group, The NZ College of Clinical Psychologists, The NZ Psychological Society, The Royal Australian and NZ College of Psychiatrists, and personal contacts of the researcher and supervisors of this project. Further details of these sources are discussed below.

*Primary Health Organisation.* The organisation has 335 member GPs. Member GPs are made up of non-specialists in the mental health and/or ID field and a specialist mental health team. This group therefore is likely to comprise of individuals of mixed experience in dealing with individuals with an ID and co-morbid mental health issues.

*ID special interest group distribution list.* Two lists of individuals with a specific interest in ID which are co-ordinated by a Clinical Psychologist. It was estimated that there were around 40-45 Psychologists combined on these distribution lists.

*NZ College of Clinical Psychologists.* This professional body of Clinical Psychologists has a number of branches nationwide within NZ. The College distributed an invitation to its members via email.

*The NZ Psychological Society.* This is a professional body of Psychologists of various psychological scopes. The society distributed an invitation to participate in the research to its members via its magazine *Connections*.

*The Royal College of Australian & NZ Psychiatrists.* This is the bi-national body for Psychiatrists operating in both NZ and Australia. The NZ branch placed an invitation to participate in the research in their newsletter.

*Personal contacts of the researcher and supervisors.* Various personal contacts of the researcher and supervisors were approached. These included individuals of various professions.

All procedures and measures were approved by the University of Canterbury Human Ethics Committee (reference number: HEC application 2013/80/LR) (Appendix A and Appendix B). All participants were informed that completion was voluntary and that they could choose to withdraw at any time. In order to access the survey, participants had to acknowledge they had read the information provided and acknowledge consent to access the online survey. See Appendix D for information provided to participants and the linked consent question.

The groups and individuals outlined above were approached regarding their willingness to complete the surveys/provide details to their members. The College of Clinical Psychologists, The Psychological Society and the special interest group (distribution list) agreed to electronically disseminate the information to their members upon proof of ethical approval. The Royal College of Australian & NZ Psychiatrists put the proposal (to provide information to its members) in front of the NZ membership committee and upon approval placed information regarding the research in their newsletter. The Primary Health Organisation required a further internal proposal regarding the project alongside evidence of ethical approval and what was being asked of the organisation. See Appendix C for a copy of research approval (Project ref: RAE0025) and conditions of approval provided by the Primary Health Organisation.

***Focus group.*** The second data collection (focus group) occurred following the conclusion of the thematic analysis of the online survey. Participants from stage one were selected and invited to participate in the focus group. No additional selection criteria were utilised for this step. All focus group participants were provided with an information pack on (a) the research rationale, (b) the format of the group discussion and (c) consent and privacy forms. See Appendix F and G for information provided and focus group consent form.

***Individual interview.*** The second data collection also involved the individual interview, which followed the conclusion of the thematic analysis of the online survey. Health practice managers in the local Canterbury region were telephoned for permission to either (a) disseminate information about the research to their GPs via email or (b) allow the researcher to present an invitation about the research to GPs at a practice meeting. One GP responded to the email invitation. This GP was provided with an information pack on (a) the research rationale, (b) the format of the interview and (c) consent and privacy forms. See Appendix H and I for information and consent forms. The GP subsequently chose to take part in an individual interview.

***Data analysis.*** Data was imported into Excel, then organised and listed in groups according to the type of health practitioner responding, i.e. Psychiatrist, Psychologist or GP. The initial data analysis step involved familiarisation with the data set itself (Braun & Clarke, 2006). Due to thematic analysis relying on the researcher identifying key patterns and meanings within the data, it was essential to understand the depth and breadth of the data collected (Braun & Clarke, 2006). Alongside familiarisation with the data set, initial notes were taken regarding concepts. These represented important information relating to the difficulties health practitioners experience when diagnosing co-morbid mental health issues in individuals with ID. While prevalence of similar information within a data set does not

necessarily equate to key themes in terms of importance, it is often an indicator (Braun & Clarke, 2006); therefore, commonly occurring themes were also noted.

The second stage of analysis involved the initial noting of codes to identify patterns and meanings to allow categorisation of the data into meaningful information (Braun & Clarke, 2006). These codes were shaped by the data and how it related to the aims of the research as interpreted by the researcher. The data entered into Excel was then separated line-by-line into meaningful units and highlighted according to the code that applied to it. Given the process outlined by Braun and Clarke (2006) and their recommendation that multiple coders can detract from the quality of thematic analysis, the researcher was the sole coder for this project.

The third stage involved the examination of all of the codes yielded in the second step of analysis and organising them into potential themes. This was achieved through the use of mind maps involving the different codes and their relationships to each other and the overarching themes (Braun & Clarke, 2006). These themes were used to guide the focus groups and individual interview further. These were recorded and transcripts produced. Information from the transcripts was then imported from Microsoft Office Word into Excel using the Tables function. A repeat of steps one to three then took place and any additional or altered data/codes and potential themes were integrated into the existing suggestions.

The fourth step of analysis involved reviewing the potential themes, identifying any that were not suitable, collapsing themes that did not warrant separate categories into each other and dividing those that required further separation (Braun & Clarke, 2006). This was achieved by examining the coherence of codes as they applied to overarching themes and adjusting as necessary (Braun & Clarke, 2006). At a broader level, examination of the individual themes occurred in relation to the entire data set. This helped to ensure that the

themes accurately reflected the meanings in the data set in its entirety (Braun & Clarke, 2006).

Finally, the fifth step involved defining, naming and describing each theme (Braun & Clarke, 2006). This involved identifying the essence of the theme, in particular how it fitted with other themes as well as within the data set as a whole (Braun & Clarke, 2006). In order to ensure the quality of the thematic analysis, the researcher interpreted data yielded from the online surveys in light of past research, as identified through the literature review (Braun & Clarke, 2006).

## CHAPTER THREE – RESULTS

### 3.1 Un-coded data: online survey

A total of 52 practitioners completed the online survey. The information collected from these questions identified half were Clinical Psychologists, just over a quarter (27%) were Psychiatrists, with a smaller number (6%) of GPs. Other health practitioner types consisted of 17% of the participants. Almost all participants (98%) had worked with an individual with an ID, with only 2% having never worked with an individual with ID. Over half (56%) of the participants reported either extensive or a lot of experience working with individuals who have an ID, although a quarter had only some, a little or minimal experience. The majority (83%) of participants felt very or mostly confident, although some (17%) felt less confident. The majority (75%) of participants' current job role involved working with individuals with ID extensively, a lot, or sometimes. A quarter of participants' current job role involved working a little or minimally with individuals with ID. The majority (83%) had experience in diagnosing psychiatric disorders in individuals with an ID. Of their current job role, just over a quarter (26%) diagnose psychiatric disorders in persons with ID. The majority (74%) of participants' current jobs involved some, a little, or minimal diagnosis of psychiatric disorders in individuals with ID. Most (85%) reported experiencing challenges when carrying out these diagnoses and the majority (87%) had referred on to other health practitioners or teams at various times.

**Table.1.** Un-coded online survey questions and answers. *Note questions listed below are abbreviated. For a list of full questions please see Appendix E.*

Question no.			Answers			
1. Agree to take test	Yes 100%	No 0%				
2. Current professional registration	Psychiatrist 27%	Clinical Psychologist 50%	General Practitioners 6%	Other 17%		

<b>3.</b> Worked with an individual with ID	Yes 98%	No 2%				
<b>4.</b> Amount of current position and experience working with individuals with an ID	Extensive 37%	A lot 19%	Some 19%	A little 15%	Minimal 10%	
<b>5.</b> Confidence working with people with ID	Very Confident 42%	Mostly Confident 41%	Sometimes Confident 11%	Mostly Unconfident 6%	Very Unconfident 0%	
<b>6.</b> Experience diagnosing psychiatric disorders in individuals with ID	Yes 83%	No 17%				
<b>7.</b> Amount current job involves diagnosing psychiatric disorders in individuals with ID	Extensive 13%	A lot 13%	Some 14%	A little 30%	Minimal 30%	Unsure 0%
<b>12.</b> In cases where you have diagnosed psychiatric disorders did you experience challenges	Yes 85%	No 15%				
<b>30.</b> Have you referred on to another professional or team when suspected psychiatric disorders	Yes 87%	No 13%				

### 3.2 Coding

In total 50 codes were obtained from the data set (Table 2). These codes were created by examining each question in the online survey with regard to each of the four groups – Psychiatrists, Clinical Psychologists, GPs and others. In addition, extra information gained

from the focus group and individual interview was added to these codes. These codes were created to represent the important elements of the responses and at a broader level across different groups of health practitioners.

**Table 2.** Codes obtained from all stages of the research.

<b>Codes</b>
1. Time:- Very short - 10mins to 1 hour/very little/on the fly
2. Time:- Short - 1 hour to 2 hours/some time pressures
3. Time:- Medium - 2 hours to 8 hours/adequate/sufficient
4. Time:- Long - one day plus/as much as required
5. Funding pressures
6. Service demand
7. No pressure to make diagnosis
8. Pressure to make diagnosis
9. Pressure to make diagnosis due to service worked in
10. Part of my role to make diagnosis
11. Reluctant to make diagnosis
12. Confident
13. Not confident
14. Moderately confident
15. Dependent on level of disability of individual
16. Working with colleagues
17. Working diagnoses
18. Overshadowing
19. Challenging behaviour vs. mental health
20. Individual communication difficulties
21. Characteristics of the ID
22. Language dependence of diagnostic systems
23. Atypical presentation
24. Flexible approach/adjust/adaptation
25. Negative symptoms often ignored, i.e. depression
26. Inconsistent information
27. Third party bias
28. Function of the behaviour – context – holistic approach
29. Lack of training/knowledge of health practitioner
30. Ignorance/discrimination towards individuals with ID
31. Lack of inter-service collaboration
32. Lack of appropriate assessment tools
33. DSM-5
34. DSM-IV
35. DSM-5 Do not use
36. DSM-IV Do not use
37. ID specific tools i.e. DC-LD/PAS-ADD/Glasgow, etc
38. No formal tools
39. Clinical interview
40. Functional assessment
41. Gather further data/behaviour observations/variety of sources/multiple informants
42. Refer to specialist service



43. Focus on a needs basis
44. Refer to literature
45. Listening to the person
46. Clinical judgement
47. Previous history, written records of individual with ID
48. Person not improving/not responding to treatment
49. Building rapport/understanding
50. Risk to self/others
51. Risk to self/others

**Coding of the online survey by questions and health practitioner groups.** The large number of codes outlined above were initially obtained from the remaining 21 questions of the online survey alongside data collected during the focus group as well as the individual GP interview. In many cases there were overlapping codes from different health practitioner groups for the same questions. In other cases, different health practitioner groups had different results. For example, when asked how much time they had to undertake a full formal assessment in order to make a psychiatric diagnosis, there were clear differences between the different health practitioner groups, with GPs having much less time than either Psychiatrists or Clinical Psychologists. Within the two latter groups, the time allowed for an assessment varied greatly from an hour, up to multiple visits and days.

**Table 3.** Remaining survey questions and resulting codes analysed by thematic analysis in health practitioner groups. *Note questions listed below are abbreviated. For a list of full questions please see Appendix E.*

Question Number	Health Practitioner Codes			
	<i>Psychiatrists</i>	<i>Clinical Psychologists</i>	<i>General Practitioners</i>	<i>Other</i>
<b>8.</b> Time to undertake assessment and make diagnosis	2 & 3	2, 3 & 4	1 & 2	2, 3 & 4
<b>9.</b> Opportunity to explore individual's background etc during assessment	2, 3 & 6	2, 3, 4, 20, 26 & 27	1, 2 & 3	3 & 4
<b>10.</b> Pressure to diagnose	5, 7, 8 & 10	5, 7, 8 & 9	8 & 9	7, 8 & 11
<b>11.</b> Confidence in diagnosis of co-morbid disorders	12, 14, 17, 18 & 19	12, 13, 14, 15, 16, 20 & 29	13 & 14	12, 14 & 16

<b>13.</b> Challenges experienced	19, 20, 21, 23 & 26	5, 18, 21, 22, 23, 25, 26, 27, 28 & 29	1, 20, 21, 23, 26 & 27	18, 25, 26, 27, 29, 31 & 32
<b>14.</b> Formal tools or systems used to come to a diagnosis	16, 35, 38, 46 & 47	16, 33, 34, 37, 39, 40, 41, 44, 46 & 47	37 & 38	37, 39, 40, 41 & 47
<b>15.</b> When uncertain what has been outcome for individual with ID and what did you do	10, 17, 36, 40, 41 & 43	5, 6, 16, 17, 29, 31, 42 & 43	17, 36 & 42	5, 16, 24, 28, 41 & 42
<b>16.</b> Anticipate uncertainties when using DSM-5 and what do you do	32 & 35	22, 23, 24, 32 & 35	17, 35 & 36	22, 23 & 35
<b>17.</b> When struggling to come to a diagnosis what steps do you usually take	16, 17, 41, 42, 43 & 44	16, 17, 41 & 42	17, 41 & 42	16, 17, 42 & 44
<b>18.</b> Third party information - How do you ensure response accuracy	24, 26, 37, 41, 46 & 47	24, 26, 37, 41 & 46	1, 27 & 41	17, 26, 27, 37
<b>19.</b> How do you control for or get around third party bias or lack of accuracy	24, 28, 29, 41, 46 & 47	24, 26, 37, 41 & 46	24, 41 & 46	26, 39 & 41
<b>20.</b> Importance placed on expressive communication when assessing mental state	15, 20, 21, 23, 24 & 27	15, 20, 23, 24, 37, 41 & 43	15, 20, 21, 23 & 24	20 & 21
<b>21.</b> How to control for impact of physical disabilities on expressive communication	24, 27, 41 & 47	4, 16, 24, 27, 37, 41, 45 & 47	27 & 45	16, 24, 27, 37 & 47
<b>22.</b> Importance placed on receptive communication when assessing mental state	15, 20, 21, 24 & 41	15, 20, 21, 26 & 27	15, 20, 21 & 27	15, 20, 21 & 27
<b>23.</b> How to control for impact of physical disabilities on receptive communication	3, 4, 16, 21 & 24	3, 4, 16, 24, 27, 37, 41 & 44	39, 46 & 49	24, 27, 37 & 41
<b>24.</b> Diagnostic criteria calls for description of thoughts/feelings and individual unable to provide how does the health practitioner get around this	24, 39, 40, 41, 45, 46 & 47	24, 27, 37, 41, 44 & 47	14, 35, 36, 38 & 46	17, 24 & 41
<b>25.</b> Do you replace	24 & 41	24, 37, 38 & 41	29, 41 & 46	27, 41 & 47

criteria (in Q.24) with anything else				
<b>26.</b> With Major Depressive Disorder how would you check if individual has feelings or worthlessness/guilt nearly every day	15, 24, 27, 28 & 41	15, 20, 21, 24, 27, 28, 41 43 & 45	3, 15, 20, 21, 24 & 49	24, 27, 28 & 41
<b>27.</b> With regard to Generalised Anxiety Disorder how would you determine if person finds it difficult to control their worry	24, 27, 37, 41, 45 & 49	15, 20, 21, 24, 27, 39, 40, 45, 47 & 49	3, 28, 40, 45 & 49	15, 20, 21, 24, 28, 41 & 47
<b>28.</b> With regard to Paranoid Personality Disorder how would you check if person is reluctant to confide in others due to fear that information will be used against them	24, 27, 28, 39, 41, 43, 45 & 49	28, 29, 41, 42 & 49	24 & 41	15, 29, 41, 45, 47 & 49
<b>29.</b> How would you check if person is experiencing delusions	15, 21, 24, 27, 41, 45, 47 & 49	15, 20, 21, 22, 28, 40, 41, 46 & 47	15, 21, 24 & 41	15, 20, 21, 28, 41, 45 & 47
<b>31.</b> When would you refer on to another health practitioner/team	6, 13, 17, 29, 42, 48 & 50	5, 6, 13, 18, 29, 31, 42 & 48	29, 42, 48 & 50	42, 48 & 50
<b>32.</b> Anything else to add	6, 23, 24, 29, 31, 37 & 38	1, 5, 6, 18, 19, 21, 23, 29, 30 & 31	1, 5, 6 & 43	35, 37 & 38

**Coding - focus group.** A total of 9 health practitioners participated in the focus group. All participants were Psychologists, with 5 within the Clinical Psychology scope and 4 within the General Psychology scope. Most (89%) were experienced in working with the ID population.

**Table 4.** Focus group main codes and supporting quotes. *Note when writing is in parentheses and italics the researcher has changed some words to protect the anonymity of the participant or others. In cases where text is in bold font and*

*parentheses, additional words or explanations have been added to provide context for the quotation.*

Code/s	Quotations
18. Overshadowing	<p><b>[In response to being asked what some of the key challenges are when trying to diagnose co-morbid mental health issues in individuals with ID]</b> “Whether people see this as part of the intellectual disability or whether they see it as a separate psychiatric diagnosis and there is just such a huge variation particularly around things like <b>[Attention Deficit Hyperactivity Disorder]</b> ADHD.”</p> <p><b>[In response to being asked what some of the key challenges are when trying to diagnose co-morbid mental health issues in individuals with ID]</b> “Often I have found in the past that sometimes behaviours, that they are quite unstable and it’s just put down to the fact they have an ID whereas in fact they are actually depressed. I have found that quite a bit lately.”</p> <p><b>[Following on from statement above]</b> “I certainly see that issue of overshadowing a lot [with] client is perceived as the problem being the ID. Anxiety disorders in particular I think are overlooked. I have had somebody say to me ‘Well, what ID person isn’t anxious?’ Depression as you find, and also <b>[Post Traumatic Stress Disorder]</b> PTSD. My particular area is trauma work so sexual abuse, and that is overlooked in the general population let alone in the ID population. It really is not recognised.”</p>
18. Overshadowing 29. Lack of training/knowledge/experience of health practitioners 31. Lack of inter-service collaboration	<p><b>[In response to being asked what some of the key challenges are when trying to diagnose co-morbid mental health issues in individuals with ID]</b> “When other mental health services who don’t have the same expertise in ID are working with someone with a mental health problem that have a co-morbid intellectual disability, they don’t always have that same expertise to pull apart and separate those two issues and so, it would be, there is not enough working together I guess is one of the problems we face.”</p>
30. Ignorance/ discrimination towards clients 31. Lack of inter-service collaboration 43. Focus on a needs basis	<p><b>[Discussing the difficulties in communication between different services and the lack less experienced health practitioners seeking expert opinion]</b> “There is often it seems for a lot of services, [that] they are more clear around who they won’t work with rather than who they will. So the moment there is anything that comes up vaguely ID, ‘Oh, that’s just totally your baby’ and instead of actually recognising this is a person with a mental illness. So there is that sort of that turf protection stuff.”</p>
31. Lack of inter-service	<p><b>[Experiencing difficulty with communication between different</b></p>

collaboration	services] “I find that being in private practice it really hard to liaise with different organisations including sections of the DHB. You’re often not in the loop.”
29. Lack of training/knowledge/experience of health practitioners	<p><b>[In response to being asked what some of the key challenges are when trying to diagnose co-morbid mental health issues in individuals with ID]</b> “I think services are afraid of the unknown and so as soon as they see the ID they pass it on and get rid of it quickly because they don’t have the expertise or they don’t have the confidence and, you know, ‘ID scares me’ for those that haven’t worked in the area.”</p> <p><b>[In response to being asked what can be done to change the lack of interest in working with individuals with ID]</b> “Well I do think it should be taught at the undergraduate degree some working knowledge of working with ID. We have lost the placements. Despite its limitations I spent many years at a psychopaedic hospital and we had a lot of students through. Hopefully they learnt a bit more of the reality. There have been psychiatric loss of placements as well of course”</p> <p><b>[Participants’ thoughts on the increasing reliance on GPs to diagnose co-morbid mental health issues in individuals with ID]</b> “It would be a big concern because I happen to know, that when I was in education, special education 5th year medical students have half a day in a special needs classroom. That is their sole exposure really to ID.”</p> <p><b>[In response to being asked should training for health practitioners involve more about ID]</b> “I mean I’m just thinking from an ID perspective I think it should be compulsory for students to have placements within ID team.”</p> <p><b>[Conversation about whether there should be more training for health practitioners about ID]</b> “At the moment, I find it very difficult to find Psychologists who have knowledge of ID now that I’ve cut back my practice. It is hard to know who to refer to onto because either the training or the experience. People are not interested in working generally with people with an ID.”</p> <p><b>[Conversation about whether there should be more training for health practitioners about ID]</b> “Yes, we all went through [<i>the psychopaedic hospital</i>]. That was a good placement and now though most of our students don’t have any, there aren’t really any supervisors in that area that are in a position to be able to take students. I think we really need to think creatively about that.”</p> <p><b>[Conversation about whether there should be more training for health practitioners about ID]</b> “I think we are very good at teaching people theory but we are not good at saying to people how</p>

to translate it into practice. So now that you know CBT, how are you going to translate it for someone that doesn't understand the concept of a distorted thought? People have got to understand the model in order for the model to be effective."

**[Conversation about whether there should be more training for health practitioners about ID]** "Most people out there aren't interested because they don't know how to adapt and yet there are resources out there, but it takes time and it's lots of time. Even the concept of an hour of therapy. Whereas it is a case of a law of thirds. You spend the first third of your session just grounding the person, so 'How are you, remember what we are here for...' The second third of the session you are actually doing the work and the last third of the session you are having to recap. So it is a very small window that you are actually lucky if you get one idea across and then this concept of 'Well, I will see you next week or next month'. Then you go through that whole cycle again."

**[Conversation about whether there should be more training for health practitioners about ID and how to attract more interest from health practitioners]** "I think exposure because my background is that when I was studying at the university I had a part time job at a *[support organisations]* residential home sort of thing, and as teenager I had exposure. I remember when I was about 16 I was asked if I wanted to assist at a *[youth]* camp for people with IDs and I had no idea what ID was back then and I said no because I had no idea and I was afraid. I didn't know what ID was. I had perceptions of the old psychopaedic hospital, because that is the perception that society had, which I think unfortunately is still there."

**[Conversation about whether there should be more training for health practitioners about ID and how to attract more interest from health practitioners]** "So maybe then the more psychology students that get exposure to some time with the ID population will open up their minds to 'Oh, this person has an ID' but you wouldn't be able to tell from the street that they did. As opposed to somebody rocking in the corner in an institution. I think that might actually open up more Psychologists to being interested in the field."

## 28. Function of the behaviour-context- holistic approach

**[In relation to conversation about overshadowing]** "Historically, if you look at the life pathways of our clients with IDs it has been quite harrowing. It has been multiple, multiple places to live."

**[In relation to conversation about overshadowing and the importance of considering an individual holistically]** "No control, no choice in who they live with."

	<p><b>[In relation to conversation the importance of considering an individual holistically]</b> “Even staff in the residential home forcing a client into the van to go to work each day because that suits the work, because there can’t be anyone there. The client doesn’t have the chance to say ‘No, I don’t want to go.’”</p> <p><b>[In relation to conversation the importance of considering an individual holistically]</b> “You even look at their education, their development or exposure to the world because I’m pretty sure that I’ve come across clients who have been diagnosed as having an ID when in actual fact, you know if you took into account their educational background, their family background and so forth, their exposure to current events in the world and so forth, they have an ID because they haven’t had that. Otherwise they wouldn’t have an ID.”</p> <p><b>[In relation to conversation the importance of considering an individual holistically]</b> “That can be the same in residential group homes as well. The culture of the place could be what the issue is, or the staff dynamics, which can be really the trigger for the person’s behaviour. I guess addressing those kind of things can be really quite difficult, because you really haven’t got a mandate to go into a provider and suggest they need to change some of their practices.”</p>
<p><b>28. Function of the behaviour-context- holistic approach</b></p> <p><b>29. Lack of training/knowledge/ experience of health practitioners</b></p>	<p><b>[Conversation about the difficulties that arise in diagnosis through lack of health practitioner knowledge]</b> “Yeah, so I guess once again that comes down to I guess the majority of general mental health services not having that expertise in either specific learning disorder or ID and so they are not recognising. They also don’t seem to, in my perspective, to be viewing things in the holistic way in which we need to. So they are not looking at schooling history, they are not looking at developmental milestones even, they are just looking at the here and now and unless you look at the developmental milestones you can’t identify whether there is an autism spectrum disorder.”</p>
<p><b>27. Third party information</b></p>	<p><b>[What some of the key challenges are when trying to diagnose co-morbid mental health issues in individuals with ID]</b> “The other part of this matter and that is often the diagnosis is made with the information provided by third party. It is rare in my experience, that the client is the lion share of the interview. It is usually ‘So, tell me what is going on for so and so,’ ‘What do you notice about...’ The lion share of the information is always coming from someone else rather than the client themselves.”</p>
<p><b>41. Gather further data/ beh obs/variety of sources/multiple informants</b></p>	<p><b>[How to overcome potential difficulties using third party information]</b> “I think if you have the flexibility to spend time and do observations, and speak to as many other people as possible and go into as many different environments as you can so that you get a</p>

	really good understanding of what is happening, then that sometimes can help and give a broader picture.”
24. Flexible approach/ adjust/adaptation	<p><b>[How to overcome difficulties in diagnosing co-morbid mental health issues in individuals with ID]</b> “I think the key thing is that assessments with our clients takes so much longer than what they do with a person who doesn’t have an ID. You’ve got to have, you know, that ability to spend that extra time.”</p> <p><b>[How to overcome difficulties in diagnosing co-morbid mental health issues in individuals with ID]</b> “I use sometimes very simple visual scales with a happy face and a sad face or numbers. When I’m assessing stress I use a thermometer with numbers on it which is quite useful.”</p> <p><b>[How to overcome difficulties in diagnosing co-morbid mental health issues in individuals with ID]</b> “I think that for me, trying to do these sort of assessments quite fast and trying to assess fitness to stand trial... [PAUSE] One thing that stands out in my mind is that often people with an ID cannot communicate about time and the order of events and differentiate between ‘what I think and feel now’ and ‘what I thought or felt then’. Or, hypothetical situations trying to get them to put themselves in the shoes either somebody else or in a different situation or different time, different person. So those are the sort of things I think we rely on quite a lot to assess psychiatric disorder usually. I just have to chuck the brakes on there and think of different ways to do that. I am always scrambling to find a new way and that’s when you fall back on asking somebody else, but sometimes that’s just pointless really especially fitness to stand trial. I have to find this person what they can get their mind around.”</p>
24. Flexible approach/ adjust/adaptation 29. Lack of training/knowledge/ experience of health practitioners	<p><b>[How to overcome difficulties in diagnosing co-morbid mental health issues in individuals with ID with regards to giving health practitioners enough and suitable training]</b> “We need to think about when we are teaching the assessment block, how we teach students to adapt their assessment style for the context and that is not coming through. That takes quite a lot of thinking - and maybe that is something that could come out of this - is how do we teach people to step away from the format when needed. Again when needed. It’s knowing how to do that flexible approach that other people have commented on.”</p> <p><b>[How to overcome difficulties in diagnosing co-morbid mental health issues in individuals with ID with regards to giving health practitioners enough and suitable training]</b> “One of the constraints that I have realised is that the clinical programme, from what I understand, has a very strict view of who can supervise on a placement, which really does restrict where they can go in terms of ID placements. In this room I know we have a complete range of</p>



	<p>scopes that we were trained in. Psychologists with a great deal of skills and expertise in areas, but with different scopes. Certainly we had the capacity to experience at various points and various placements supervised by a variety of psychologists of various scopes. Some flexibility with that might really enable that experience to be broadened.”</p>
<p>1. Time 5. Funding pressures 6. Service demand</p>	<p><b>[In response to questioning does the system allow enough time to complete an adequate assessment]</b> “That is one of the biggest challenges we see: is that they don’t want time, they just want the assessment done and a diagnosis made. It seems to be a real battle to get them to understand that extra time is needed, especially with the courts.”</p> <p><b>[In response to questioning does the system allow enough time to complete an adequate assessment]</b> “They’ll even let you write a report without seeing somebody now, or they will encourage you to. So I’m not thinking just specifically in the ID context now, but I find having enough time to properly assess one of the ID clients is a real challenge in the framework of the section 38 report.”</p> <p><b>[Following on from statement above]</b> “I had the same battle with <b>[Child Youth and Family Services]</b> CYFS and actually mental health services generally - particularly inpatient psychiatric wards who want assessments within a week because the behaviour planning is all important, but it is just not possible to do an assessment within a week. There is not much comprehension of that.”</p> <p><b>[Following on from statement above]</b> “I’ve spent that last few days going through records of a client and writing a report and I’ve been paid one hour, so that puts it into some perspective.”</p> <p><b>[Other challenges health practitioners experience when trying to diagnose co-morbid mental health issues in individuals with ID]</b> “One of the other problems with NZ specifically that I find is that a large amount of the population live remotely <b>[PAUSE]</b> and certainly a few weeks ago I did a private job on the West Coast for the DHB over there and I had to go and do a diagnosis and an assessment of a young person in a day, and I was still with travel three days doing the one job <b>[PAUSE]</b> and I couldn’t have split that up anymore or else it wouldn’t have been viable. I couldn’t have possibly done the work, and then they don’t have any services and they always have to hire people from Christchurch to do this. So in those areas where they don’t have the expertise there does seem to be a real problem because you just don’t have that luxury of time and it’s got nothing to do with the stakeholders demanding, it’s the fact that there is just no other way of doing it.”</p>

	<p><b>[In relation to conversation the importance of considering an individual holistically]</b> “I was just going to say, I love the question ‘Is the system depressed?’ Because a lot of our east clients live in places where the staff are overworked and underpaid.”</p> <p><b>[Services being protective over which individuals they will see and the relation to funding]</b> “There is scarce resources.”</p>
<p><b>32. Lack of appropriate assessment tools</b></p> <p><b>37. ID specific tools i.e. DC-LD/PAS-ADD/ Glasgow</b></p> <p><b>44. Refer to literature</b></p>	<p><b>[Conversation regarding some experiences of previous incorrect assessment and diagnosis of individuals and the reason for this]</b> “In terms of mental health diagnoses, I think they are also often seriously flawed [PAUSE] in terms of, if you take something like the <b>[Beck Depression Inventory II]</b> BDI-II, I can’t see the relevance of it for our client base in terms of some of those questions. Some of those questions are just not appropriate, and yet there are other tools out there that are normed for this population group but no one seems to be using them. So instead of using the Beck, [you can use] the Glasgow Depression Scale. Instead of using the <b>[Beck Anxiety Inventory]</b> BAI there is the Glasgow, which is normed and yet no one is using these things and yet diagnoses are being made on the basis of that.”</p> <p><b>[Question regarding whether the clinician uses, and how they find the DSM-V-TR]</b> “I still pore over the DSM-IV and make comparisons with the literature as to how it might be presented differently because of the developmental levels.”</p>
<p><b>1. Time</b></p> <p><b>20. Individual communication difficulties</b></p> <p><b>22. Language dependence of diagnostic systems</b></p> <p><b>24. Flexible approach/ adjust/adaptation</b></p>	<p><b>[Importance of understanding context of individual’s difficulties and using diagnostic questions in an appropriate form]</b> “When you ask somebody a question you know, like DSM-IV or whatever [PAUSE] you know, “Are you feeling this?” or “Are you feeling that?” <b>[AND]</b> the way in which you phrase it has such a potential to skew the response because of suggestibility in our clients and you’ve got to really think about how you phrase things. My experience has been that when people are really under pressure time-wise from wherever the referral has come from, their ability to say ‘No, I’m going to take a couple of days to think how am I going to phrase these questions’ goes out the window. So they just ask them in a very automatic, you know, ‘Are you hearing voices? Are you thinking of killing yourself? Do you have a plan? Where would you do this?’ They are not actually thinking that the person is answering in a very concrete way to a very, what they think is a good way to answer this, rather than phrasing it in a different way.”</p>
<p><b>30. Ignorance/ discrimination towards individuals</b></p> <p><b>45. Listening to the person</b></p> <p><b>49. Building rapport/ understanding</b></p>	<p><b>[Considering the developmental age span and the benefits to health practitioners in working with individuals with ID ]</b> “I think that, you know, people who are practicing with people with ID, that experience brings you back to the very core of all assessment. Everybody in an ethical age, basic respect, preserving people’s dignity, allowing them to express themselves adequately... That stuff is driven home more by assessing someone with an ID.</p>

	<p>That is perhaps more of the added value of that experience and being able to transfer that into all diagnoses.”</p> <p><b>[Following on from statement above]</b> “It is respect, isn’t it? Because they are not used often to really being given that respect. And you give that and (my instance) you give the hour of therapy. Which also, and it is I know for a lot of people, but it is quite also special because nobody sits with them for an hour and talks and listens.”</p>
<p><b>24. Flexible approach/adjust/adaptation</b></p> <p><b>43. Focus on a needs basis</b></p>	<p><b>[Altering approach to fit the needs of the individual]</b> “But them changing their approach and adapting that to fit the needs of the clients, and in this case they needed to allow for a whole different set of approaches.”</p>
<p><b>5. Funding pressures</b></p> <p><b>28. Function of the behaviour-context-holistic approach</b></p> <p><b>43. Focus on a needs basis</b></p> <p><b>50. Risk to self/others</b></p>	<p><b>[Considering the individual holistically and the ethical dilemmas health practitioners encounter]</b> “I’ve got a client who received as <b>[Wechsler Intelligence Scale for Children-IV]</b> WISC-IV score of 69 and whose adaptive functioning was really low. He had the appearance of being very impaired but given the neglect that he has suffered and the attachment issues, it’s really, it’s quite possible the ID isn’t organic. It’s quite possible if the circumstances were different he wouldn’t seem so impaired and I have been asked to re-test him, which I wouldn’t do right now because he is not in a settled environment. There is the ethical dilemma though that if I tested him and he comes out as not having an ID, he wouldn’t be eligible for services and he is a young man that is likely to need services, otherwise he is likely to reoffend. So it is a real issue. And on the other hand, if he requires a different kind of intervention then that seems important as well.”</p> <p><b>[Ethical dilemmas health practitioners encounter]</b> “It’s used as a gatekeeping now to funding, the diagnosis, isn’t it?”</p> <p><b>[Ethical dilemmas health practitioners encounter]</b> “It becomes about what is best for the client versus what is best for society, you know? And yet society wants the diagnosis so we can put them away somewhere, house them somewhere. But at the end of the day it may not be what is best for the client.”</p> <p><b>[Ethical dilemmas health practitioners encounter]</b> “Certainly with our service, there is quite a few clients who really are above and not diagnostically ID, but they have been with the service quite a few years and it is kind of the best outcome for the client, so there is a bit of flexibility there, which is good. But there are some cons there, like the person might see themselves as having an ID when they don’t on paper, but it’s the best outcome for them really.”</p> <p><b>[Ethical dilemmas health practitioners encounter]</b> “But is this not the issue where we diagnose a mental health issue, say</p>

schizophrenia or depression say, but we don't know what to do so it's easier to say 'Well, I'll put them under the ID category anyway so at least that way they'll be kept safe. I don't quite know what to do therapeutically except throw medicine at this', but in terms of actual therapy, sometimes people are being kept in actual ID services because it's deemed that that is where they will be kept safe and looked after. So this whole concept of your IQ is sometimes related to, therapeutically, we don't know. So we put it all under the banner of the ID. So as long as they are kept in an ID home this whole issue of their depression or anxiety will at least be managed by the paternalistic care. The real issue is 'Now that I have a label of depression for this person, what am I going to do with this person, and is my label of depression for this person accurate in the first place?', which is what you were asking."

During the focus group many of the same codes emerged as those obtained from the online survey. Many of these codes and themes were explored in greater detail in the focus group, which allowed for greater contextual analysis than was possible in the online survey. In addition, critical exploration was undertaken of how such challenges are overcome. This aligned with the aim of the focus group to provide rich and in depth information and perspectives on some of the challenges of diagnosis for this population and how health practitioners overcome these.

**Coding - individual interview.** As noted above, only one GP chose to participate in an individual interview. As with the focus group, the individual interview with the GP yielded many of the same codes as those from the online survey (Table 5). The interview with the GP allowed for greater in-depth exploration of the data initially gathered from the online survey. Questions were developed on the basis of examining the data collected in the online survey and identifying areas through which further questioning could yield more depth and context. For instance, the participant was questioned as to how many of the individuals they see have ID and co-morbid mental health issues as well as how they respond in assessing particular disorders. The individual interview was conducted with a GP who has considerable experience working with individuals with ID: approximately 10% of the individuals they see

have an ID, with approximately 60% of those individuals also experiencing co-morbid mental health difficulties.

**Table 5.** Individual interview main codes and supporting quotes. *Note writing in parentheses and italics has been altered by the researcher to protect the anonymity of the participant. In cases where text is in bold font and parentheses, additional words or explanations have been added to provide context for the quotation.*

Code/s	Quotations
23. Atypical presentation	[Challenges faced by health practitioners in diagnosing co-morbid mental health issues in individuals with ID] “It’s never what it looks like.”
20. Individual communication difficulties	[Challenges faced by health practitioners in diagnosing co-morbid mental health issues in individuals with ID] “Communication can be difficult.”  [Challenges faced by health practitioners in diagnosing co-morbid mental health issues in individuals with ID in relation to communication] “You have to ask; they often won’t volunteer”
19. Challenging behaviour versus mental health	[Challenges faced by health practitioners in diagnosing co-morbid mental health issues in individuals with ID] “It is difficult to tease out what is behaviour and what is psychiatric.”
19. Challenging behaviour versus mental health	[Challenges faced by health practitioners in diagnosing psychosis in individuals with ID] “Challenge of differentiating between behaviour responses due to environment or psychiatric disorders.”
28. Function of the behaviour-context-holistic approach	
41. Gather further data/beh obs/variety of sources/multiple informants	[Differences from diagnosing in people without an ID] “Need to focus on behavioural observations for people with ID.”
1. Time	[Time to assess] “15 minutes normally, but 30 minutes if knowing I need longer.”
36. DSM-IV not used	[Does health practitioner use tools] “No, I don’t use DSM-IV. If it got to that level I would refer on.”
42. Refer to specialist service	[What health practitioner does when they encounter a challenge] “Refer on to [ID and psychiatric dual services team].”

<b>15. Dependent on level of disability of individual</b>	<b>[Confidence in diagnosing]</b> “Milder forms – confident.” <b>[Confidence in diagnosing]</b> “More complex - would seek advice.”
<b>16. Working with colleagues</b>	<b>[What health practitioner does when they encounter a challenge]</b> “Talk it through with other staff.”

### 3.3 Themes

In total, 11 core themes emerged and were apparent across all levels of the data collection, although to varying degrees. The 11 core themes are outlined and described below in order of strength in relation to the number of times they were discussed in the data.

*Note: in cases where text is in bold font and parentheses, additional words have been added to provide context for the quotation.*

**Holistic approach - person in context.** Many health practitioners described the importance of considering the individual with an ID in context, but for people with an ID this often appears to be more difficult to achieve than for the general population. In order to consider an individual in context, it is crucial to examine their historical background, access to education, environment, control over their own life and living circumstances. For people with an ID, in some cases it may be difficult to gain access to this information due to either a lack of documentation, difficulty of the individual in expressing their experience, or the subjectivity of having to rely on third party information. This is particularly the case if the third party informant has a different perspective, agenda or finds it difficult to recognise the importance of certain factors in the individual’s life. These issues are particularly pertinent if the individual has difficulty communicating effectively.

The importance of viewing someone from a holistic approach involves a health practitioner searching for predisposing factors, precipitating conditions, environmental, triggering, perpetuating and protective factors. This aids in comprehending and making sense of an individual’s actions, understanding why a difficulty is occurring for the individual, and how to approach treating their problems. A holistic approach also involves understanding

other factors, such as the individual's ability to have control of their own supports and prerogative over their own choices. In addition it is important to consider the social stigma and expectations that may potentially affect the individual. During the focus group this theme occurred repeatedly and in particular when considering individuals for whom coming to a diagnosis was challenging. A Clinical Psychologist illustrated this in the description of coming to an understanding of what was occurring for an individual:

*"I'm not just going to assess you, I'm going to assess all of the system around you. Because it might not be about you, it might be about the system around you is crap and actually that system might be depressed and maybe they are the ones that need medication or whatever to cope." In the break we were talking about a client of mine who was diagnosed with Depression, and alarm bells were going off in various quarters because he wasn't eating, he wasn't sleeping, he was staying up all hours of the night, he had lost all interest in just about everything. To cut a long story short, what had happened was at the tender age of 16 he has discovered Minecraft and Clash of the Clans, which means he wants to play his computer game all day, all night and doesn't want to lose what he calls his 'place in the game', and so he is not eating, not sleeping. What really needs to be assessed is the parental system and the home environment because he is sleeping on the couch. The parents go to bed, poor socio-economic environment, he is sleeping on the couch and he just stays awake and just plays his game. Yet he was the one that was placed on the anti-depressant medication because someone had seen fit to see all of these things as ticking boxes [meeting criteria for depression]."*

**Sitting with uncertainty.** This theme relates to the need of health practitioners to sit with a working and/or evolving diagnosis when working with this population. It often involves carrying out repeated observations across varied settings, talking to multiple

informants and tracking changes across time. It also relates to the often inconsistent information provided by third party informants. Due to the difficulties many individuals with an ID experience in effectively communicating, there is a heavy reliance on third party information.

A Psychiatrist stated that when working with this group it is:

*“Almost always a working diagnosis.”*

Using third party information however can cause difficulties if evidence is inconsistent. For example, a GP in the online survey described one challenge as:

*“Conflicting information among informants.”*

As such, participants indicated the importance of not coming to a diagnostic conclusion too early in the diagnostic process and instead erring on the side of caution. This calls for clinicians to work with minimal information and remain open minded regarding alternative explanations for a client’s presentation.

**Communication difficulties.** This theme relates to difficulties between a health practitioner and an individual with ID communicating effectively. These difficulties may relate to the expressive and/or receptive communication problems that an individual with an ID experiences. They could also relate to the health practitioner’s difficulty in adjusting their communication or comprehension of what the individual is trying to express. Many participants in the online survey discussed difficulties in diagnosing individuals who have an ID with a co-morbid psychiatric disorder due to communication difficulties. One Psychiatrist directly stated a challenge they had experienced in diagnosis related to:

*“Verbal deficits of the individual (both in terms of receptive and expressive),”*

A Clinical Psychologist in the focus group described some of the difficulties they experience when trying to communicate and understand a person’s capacity to stand trial:



*“One thing that stands out in my mind is that often people with an ID cannot communicate about time and the order of events and differentiate between ‘what I think and feel now’ and ‘what I thought or felt then’. Or, hypothetical situations trying to get them to put themselves in the shoes [of] either somebody else or in a different situation or different time, different person. So those are the sort of things I think we rely on quite a lot to assess psychiatric disorder usually. I just have to chuck the brakes on there and think of different ways to do that. I am always scrambling to find a new way and that’s when you fall back on asking somebody else, but sometimes that’s just pointless really, especially fitness to stand trial. I have to find this person what they can get their mind around.”*

**Lack of health practitioner’s knowledge/experience.** Health practitioners’ experience and knowledge in working with individuals who have an ID was repeatedly discussed throughout all stages of the data collection as a factor impacting upon the correct assessment and diagnosis of co-morbid psychiatric difficulties. Experienced health practitioners, such as those in the focus group, discussed less experienced health practitioners as having difficulties correctly understanding or diagnosing co-morbid disorders:

*“Outside of that, when other mental health services who don’t have the same expertise in ID are working with someone with a mental health problem that have a co-morbid intellectual disability, they don’t always have that same expertise to pull apart and separate those two issues and so it would be, there is not enough working together, I guess is one of the problems we face.”*

Less experienced or knowledgeable health practitioners (in relation to working with individuals with an ID) described feeling less confident in diagnosing individuals with a co-morbid disorder and instead relied heavily on referrals to specialist services.

**Atypical presentation.** Many individuals who have an ID experience co-morbid psychiatric disorders in a very different way to what is considered the ‘norm’ (Mohr, Tonge, & Einfeld, 2005). This means that the behaviours and symptoms of a disorder may not present in the expected manner such as that identified by general diagnostic classification systems such as the DSM-5, DSM-IV-TR and the ICD-10. These manuals were originally developed to reflect the mainstream population and as such only included a very small number of individuals in the low average and below average range of IQ (Moss, 2012). This variance in presentation may occur for a variety of reasons, such as a lack of verbal capacity, lack of identity or role, and comorbid medical conditions, all of which can affect the way in which a psychiatric condition can manifest. These can result in it being very difficult to adequately assess an individual for co-morbid psychiatric difficulties when they vary so considerably from difficulties outlined by the major diagnostic systems available. A large number of participants during all stages of the research described experiencing challenges and difficulties when an individual with an ID presents with an atypical presentation. One Psychiatrist described a challenge they face as being:

*“Atypical presentation (behaviours displayed often fall outside traditional diagnostic systems).”*

**Overshadowing-characteristics of ID/mental health difficulties/challenging behaviour.** Overshadowing refers to symptoms of psychiatric difficulties being inaccurately attributed to the individual’s ID (Ministry of Health, 2013). It also encompasses health practitioners giving unwarranted weight to the ID as explanation for an individual’s presentation (Mason, J., & Scior, K, 2004). As the individual’s ID is often the most visible and salient factor upon presentation, this can result in the practitioner overlooking or minimising other factors that may contribute to their difficulties. Many participants, but in particular those who were less experienced in working with people with ID and less

confident, described experiencing difficulties in teasing apart behaviours or symptoms that were due to psychiatric disorders and those due to the ID itself. Differentiation between a difficulty being due to the ID or a separate psychiatric disorder can impact on other factors, such as determining which mental health team becomes involved in an individual's care. One Psychiatrist described this as:

*“Artificial differentiation between ID or psychiatric with implications as to which service becomes involved.”*

**Time pressures.** This theme relates to the time pressures a health practitioner may experience when being asked to diagnose an individual who has an ID with a possible co-morbid psychiatric disorder. Time pressures may relate to the time within which a health practitioner is allowed or expected to assess and diagnose an individual. It can also relate to pressures from third parties, such as funding bodies or caregivers, who may not understand the time requirements of an assessment or report. This may also relate to budgeting constraints, environmental factors (i.e. where individuals and health practitioners are located, restricting available time for assessment or observations) or service demands, as in how many individuals a health practitioner is expected or able to see.

Individual health practitioner's perceptions of what is an acceptable time frame to assess an individual varied considerably, both within and across health practitioner groups. During the focus group most participants who were highly experienced in working with individuals with an ID discussed pressure and lack of understanding from third party bodies such as the courts, Accident Compensation Corporation (ACC) or even other mental health groups. In addition, many outlined the difficulties that these groups have in seeing or understanding the unique requirements of the ID population in comparison to those without an ID. For example, one Ppsychologist stated:

*“Yes, the courts - they’ll even let you write a report without seeing somebody now, or they will encourage you to.”*

Another stated:

*“I had the same battle with CYFS and actually mental health services generally, particularly inpatient psychiatric wards who want assessments within a week because the behaviour planning is all important. But it is just not possible to do an assessment within a week. There is not much comprehension of that.”*

GPs in particular, both in the online survey and individual interview, outlined having very limited time with which to work with individuals in general.

**Societal expectations and understanding of ID.** This theme involves individuals, other health practitioners and wider societal understanding of the unique attributes and needs of individuals with ID. It also includes societal and health systems’ difficulties in adjusting expectations, such as the time an individual with ID required for assessment, the ability of the individual to comprehend and retain information, as well as service provision in light of these unique attributes and needs. Many health practitioners raised frustration with a lack of understanding (and at times, ignorance and discrimination) from others towards individuals who have an ID and their needs. For example, a Clinical Psychologist in the online survey stated one challenge in working with this population includes:

*“[An] Unwillingness by health system to address lack of understanding and provision of service for this population.”*

Another stated that there is:

*“Poor awareness of mental health rates for people with an ID.”*

During the focus group this was explored further in terms of the history of care and societal understanding of individuals with ID. Historically it would appear that society and

health systems struggled to recognise the individual and unique ways in which mental health could manifest in persons with IDs. One Psychologist illustrated this during the focus group:

*“I remember when I was about 16 I was asked if I wanted to assist at a [youth] camp for people with ID’s and I had no idea what ID was back then and I said no because I had no idea and I was afraid. I didn’t know what ID was. I had perceptions of the old psychopaedic hospital because that is the perception that society had, which I think unfortunately is still there.”*

**Health practitioner frustration and emotive use of language and adjectives.** This theme relates to the frustrations that many participants expressed with various aspects of their work, including other health practitioners and resource pressures, whilst working with the ID population. It also relates to the emotive use of language and adjectives by participants in this study. This was particularly evident from the data collected during the online survey. For example, one Clinical Psychologist described:

*“Colleagues in mental health - ignorant, discriminatory and unprofessional in their understanding and behaviour towards individual with ID and mental health diagnosis.”*

Such strong use of language may have occurred due to the anonymous nature of the online survey, allowing participants an outlet for their frustrations without reprisal.

**Diagnostic system – high verbal criteria/taxonomy requirements.** This theme involves the difficulties experienced by health practitioners of diagnosing mental health issues for people with an ID due to the diagnostic systems being heavily based in (and reliant on) a verbal taxonomy. These difficulties were raised repeatedly at all stages of the research. Concerns centred on a system that is primarily designed for people of average intellect without taking into account individuals who may not possess average communication skills then being assessed within that system. As such, a number of participants described the need

to ‘soften’ diagnostic criteria or think about non-verbal alternatives to adequately assess this. Participants also described some situations where it may be impossible to assess specific criteria depending on the capacity of the individual to communicate. For example, when asked in the online survey ‘How would you check to establish whether the individual with an ID is experiencing delusions?’ a Clinical Psychologist answered:

*“Only possible for individuals with mild ID, not moderate or severe.”*

Some health practitioners describe using alternative diagnostic systems designed specifically for individuals with ID, such as the DM-ID, DC-LD and the PAS-ADD.

**Funding pressures.** This theme involves the pressures that health practitioners experience in relation to funding when being asked to diagnose an individual who has an ID with a co-morbid psychiatric disorder. Participants identified pressures resulting for a number of reasons, including only being able to see a certain number of individuals or having limited time with individuals due to funding of a service. External funding, organisations the health practitioner works for, or agencies such as the courts or ACC may also place budgetary limits on assessments, therefore limiting the time a health practitioner may be able to spend assessing an individual.

The pressures may also relate to individuals with an ID not getting funding due to a lack of a specific mental health diagnosis and therefore not being eligible for service provision. For example, in relation to question 10 in the online survey, ‘Is there pressure on you as a health practitioner to make formal mental health/psychiatric diagnosis?’ a Clinical Psychologist stated:

*“Yes, in particular if it involves extra funding for the individual or their access to additional services/assistance.”*

At times these pressures may come from third parties such as service providers. For instance, residential homes may rely on residents having a mental health diagnosis to identify their specific needs and supports, therefore allowing for an increase in funding.

Funding pressure may also arise due to the health practitioner's own interpretation of what an individual with an ID may require in terms of support. In the focus group this theme emerged strongly when discussing the dilemma health practitioners face in that some diagnoses can result in much needed additional funding. However, once an individual recovers and the funding is removed, there is an increased risk that the loss of support may precipitate other critical issues. One Psychologist in the focus group, explained:

*“Certainly with our service there is quite a few clients who really are above and not diagnostically ID, but they have been with the service quite a few years and it is kind of the best outcome for the client, so there is a bit of flexibility there, which is good. But there are some cons, there like the person might see themselves as having an ID when they don't on paper, but it's the best outcome for them really.”*

*\*It should be noted that some of the data gathered was strong and emotive in nature. As such, some of the themes reflected above may have appeared to have stronger support than was actually the case.*

### **3.4 Summary**

The results of the survey revealed a wide range of issues facing health practitioners when diagnosing mental health issues in an individual with an ID. Several of the themes can be seen to overlap and are interrelated. Through the process of coding the data collected from the online survey, focus group and individual interview with the GP, 11 core themes were identified in relation to challenges health practitioners face. These ranged from resource issues such as time, funding and scope of services through to experience and attitudes of the health practitioner and, at a wider level society, alongside issues of the characteristics of the

individual, their ability to communicate and inappropriate diagnostic tools and systems.

These varied themes illustrate the complexity facing health practitioners working in this field.

Specific ways in which health practitioners overcome the difficulties associated with diagnosing co-morbid mental health difficulties in individuals with ID also emerged in the study which are linked to the above themes.



## CHAPTER FOUR – DISCUSSION

Individuals with ID are approximately 40% more likely to experience a co-morbid mental health issue compared to those without an ID (Werner & Stawski, 2012). Yet due to the unique constellation of traits and characteristics of individuals with ID (among a variety of other factors), there are additional challenges to diagnose these (Moss, 2012; Pruijssers et al, 2014; Edwards et al, 2007; Jess et al, 2008; Langlois & Martin, 2008; Spendelow, 2011). This research aimed to examine the specific challenges that health practitioners face when trying to diagnose a co-morbid mental health issue in a person with ID and how those practitioners think about and overcome the challenges.

Multiple layers of factors emerged, all of which can combine to contribute to the various difficulties experienced by health practitioners. These factors included the historical background and care of the ID population generally, unique traits of the individual with an ID, societal and health practitioner attitudes, the medical model underpinning various approaches, lack of health practitioner interest, knowledge and experience in working with this group, changing models of care, resourcing issues, and communication factors. In addition, it is acknowledged that there is no easy or obvious solution to provide a ‘quick fix’ or ‘one size fits all approach’ to overcome these issues (Werner & Stawski, 2012; Ministry of Health, 2013; Chaplin et al, 2010).

Despite these complicated and multi-layered challenges, it was apparent during the gathering of data that, within the field, there are dedicated and passionate health practitioners intent on providing the individual with an ID with the best possible care and service. This was demonstrated by the strong and emotive language used by some health practitioners in relation to perceived injustice in the provision of care for individuals with ID and their perceived discrimination by other health practitioners less familiar in working with the population. Most, if not all, participants in this research appeared dedicated to providing

accurate diagnoses of mental health issues to ensure the best possible outcomes for the individual with an ID, in spite of the many difficulties that can preclude this.

From the thematic analysis of the data, 11 core themes were identified. These included (in order of most frequent occurrence) (1) holistic approach - person in context, (2) sitting with uncertainty, (3) communication difficulties, (4) lack of health practitioner knowledge/experience, (5) atypical presentation, (6) overshadowing-characteristics of ID/mental health difficulties/challenging behaviour, (7) time pressures, (8) societal expectations and understanding of ID, (9) health practitioner frustration and emotive use of language and adjectives, (10) diagnostic systems - based on high verbal criteria/taxonomy requirements, and (11) funding pressures.

#### **4.1 Themes**

**Holistic approach - person in context.** The importance of considering a person within the wider context of their lives is crucial for any individual experiencing mental health concerns, whether or not they have an ID; people do not exist in a vacuum and multiple layers of influence can impact upon peoples' lives. Considering a person in a holistic manner was the most common theme endorsed by participating health practitioners. Health practitioners usually, as part of their practice, consider all elements of a person's life that may have caused or contributed to the situation that they currently present.

For individuals with an ID, considering context can pose additional challenges above and beyond the usual. These difficulties may relate to either or both receptive and expressive communication on the part of both the individual with ID and the health practitioner. Health practitioners may struggle to adapt their communication style to suit the specific needs of the individual with an ID, such as difficulty in simplifying complex questions to ensure they are understood by the individual with ID. Difficulties may also be related to accessibility of

historical data, such as schooling or experiences the person had in their past for example being institutionalised. Many health practitioners referenced difficulty in establishing or accessing unbiased information from caregivers. Caregivers, like all people are influenced by their own experiences and beliefs, which in turn impact upon what an individual deems important. As such, this may influence the type of information that a caregiver passes onto a health professional. If an individual finds it difficult to communicate effectively, it can pose significant challenges for health practitioners to establish the context within which the person's difficulties have arisen. These difficulties may be compounded by potentially biased information presented by caregivers. In turn however, if a health practitioner is able to examine the presenting difficulties contextually, this can assist in overcoming the challenges associated with correctly diagnosing mental health difficulties for an individual with ID. For instance, if a health professional can establish that an individual with an ID is being given little prerogative over their own life whilst living in a residential home, this may indicate that the individual could be demonstrating anxiety through challenging behaviour because of a lack of freedom of choice and independence. A number of health practitioners mentioned the importance of formulation and understanding the wider system around the individual in order to understand their difficulties.

It is crucial to recall that a key aim of deinstitutionalisation was to reintegrate individuals with ID back into general society and to normalise the difficulties that a person with an ID experiences (Milner et al, 2008). Yet in spite of these ideals, many challenges have been encountered. This is particularly true for the individual with ID achieving a fulfilling and recognised social role, as well as overcoming traditional attitudinal barriers (Bray & Gates, 2003; O'Brien & Lyle O'Brien, 1995; Chaplin et al, 2010). For many individuals with ID, social contact with those outside their own peer group remains elusive, further promulgating the idea of separation of those with ID and those without ID (Lemay,

2006). Having a clear and identified social role for any individual remains crucial and some researchers suggest that this is at the very centre of maintaining ‘good’ mental health (Lemay, 2006). As such, for many individuals with ID, difficulties remain in leading satisfying and fulfilling lives (Bray & Gates, 2003; Milner, 2008; Chaplin et al, 2010, Rashid, 2012), putting them at an increased risk of developing mental health difficulties (Bray & Gates, 2003; Milner, 2008; Chaplin et al, 2010, Rashid, 2012).

In addition to difficulties integrating effectively into society, a number of participants in both the online survey and focus group mentioned difficulties regarding individuals with ID having prerogative over their own lives. For example, in the focus group one Psychologist outlined their experience, stating:

*“Even staff in the residential home, forcing a client into the van to go to work each day, because that suits the work, because there can’t be anyone there. The client doesn’t have the chance to say ‘No, I don’t want to go.’”*

This statement outlines the on-going difficulty in balancing societal perspectives that individuals with ID should have choice and determination over their own lives against systemic restrictions. These include factors such as funding and time constraints as well as a lack of understanding of the impact of a person having their personal freedom impinged upon.

### **Sitting with uncertainty.**

Many participants outlined challenges associated with clearly identifying the specific mental health diagnosis that the individual with an ID was experiencing. A large number of participants identified the need to use a working diagnosis for many of the individuals with ID and co-morbid mental health difficulties. This theme ties in closely with a number of other themes identified during this research. One of the most obvious of these is that mental health difficulties can look very different when experienced by people with ID; in other words, they

may have an atypical presentation. This is supported by previous research, which indicates that it is common for mental health difficulties to present differently in people with ID as compared to what is expected for people without ID (Edwards et al, 2007; Langlois & Martin, 2008; Spendelow, 2011). If a mental health difficulty looks different from that described by diagnostic criteria in mental health manuals, health practitioners either have to adjust criteria to provide a diagnosis, or postpone providing a diagnosis. This can create a significant dilemma for health practitioners, as adjusting diagnostic criteria goes largely against training and research. A resulting diagnosis may be inexact, with no easy way to control or monitor consistency of health practitioners' altered diagnoses. If a health practitioner does not provide a diagnosis, other consequences may occur. One of those most commonly referred to in this study was the potential loss of funding or support for the individual with ID.

Sitting with uncertainty in terms of diagnosis can also relate to diagnostic systems largely being created with reference to individuals who do not have an ID, and that the disorders often have high verbal criteria. As discussed in the section above, due to the communication difficulties many individuals with ID experience, it can be extremely difficult for health practitioners to identify the specific issues affecting the individual.

Another difficulty that is likely to relate to this theme is the considerable number of health practitioners who are not confident working with individuals with an ID but who nevertheless encounter individuals with an ID or are expected to provide preliminary work before an individual is appropriately referred on to an ID specific service (Dovey & Webb, 2000; Iacono et al, 2003; Taua & Farrow, 2009). Whilst in this study a large number (83%) of participants were generally confident in working with the ID population, a high proportion (17%) were 'sometimes' or 'mostly' unconfident when working with individuals with ID. This suggests that there are a number of health practitioners working with individuals with ID

without the necessary skills and knowledge to carry out this work effectively. This could potentially lead to the increased risk of an incorrect diagnosis being made early and result in worse outcomes for the individual.

Many participants in this study discussed the need for a flexible approach when working with individuals who have an ID and co-morbid mental health difficulty. A number believed that being flexible, both in terms of thinking and approach, were central to overcoming challenges posed when trying to accurately diagnose these difficulties. Ideas related to being flexible involved utilising varied methods of collecting information, such as in-situ and repeated behavioural observations across time and settings, and further corroboration of third party information. Other suggestions included adapting approaches to communication, such as through picture or facial expression cards, examining the individual's situation from a holistic perspective, and using trial and error treatment options. Many participants emphasised the importance of seeking guidance from additional experts and specialists in the field and working collaboratively with colleagues. The NZ Ministry of Health (2013) report that in prior studies, GPs have suggested that access to specialists on ID (either by phone or email) would be of use. The Ministry of Health (2013) stated that this strategy has been used by health practitioners when an individual experiences a psychiatric disorder, however research as to the effectiveness of this strategy has not yet been conducted. Other health practitioners suggested utilising ID-specific diagnostic tools and systems, such as the Glasgow Depression Scale, Glasgow Anxiety Scale, PAS-ADD, DC-LD and others. McIntyre (2011) outlines the importance of using specialised instruments designed for the ID population, but qualifies that these are still imperfect and would benefit from further refinement. Perkins (2007) states that whilst there are specialist tools available, often GPs do not have access to them and instead it is more likely that only specialist ID services hold these tools.

**Communication difficulties.** Communication difficulties affect a considerable number of individuals with ID (Iacono et al, 2003); these difficulties can involve both receptive and expressive communication (Iacono et al, 2003; Werner & Stawski, 2012). Previous research has indicated that many health practitioners are concerned about the potential communication difficulties between individuals with ID and health practitioners (Iacono et al, 2003; Mohr et al, 2002b; Hughes, 2009; Moss, 2012) and that these difficulties may impact upon the health practitioner's ability to accurately identify the mental health difficulties affecting the person with an ID (Iacono et al, 2003; Mohr et al, 2002b; Hughes, 2009; Moss, 2012). A number of health practitioners of varied experience raised concerns that communication between themselves and individuals with ID was a challenge they had encountered.

Given that diagnostic systems used by health practitioners are heavily based on a verbal taxonomy, difficulties in communication pose significant challenges for individuals with ID. This is particularly the case when the individual with ID is either unable to either understand verbally posed questions and/or respond in type. Within the online survey the majority of participants did not identify ways to control for difficulties in communication, whether they were receptive or expressive, apart from seeking information for informants other than the individual with ID.

Another concern resulting from communication difficulties is the type of alternative sources that may be used to gather information and how to ensure their accuracy and reliability. Many participants identified third party information provided by parents, caregivers or support staff as a key source of gathering additional data, but acknowledged the risk of potentially biased/uncorrobrated information. This can be a helpful way for health practitioners to gain insight into the difficulties the individuals with an ID experience from those who look after or are most closely associated with the individual with an ID. However,

it also poses some potential difficulties: third party informants have their own unique life experiences and emotions that contribute to their perception of events and behaviours, and as such they may inadvertently provide biased information or leave out key information that the health practitioner may require. Health practitioners also need to be open and aware of the possibility that (in some cases) respondents may also be party to other agendas unknown to the assessing health practitioner. This could range from trying to access additional funding for a diagnosis that may not be accurate to providing information that allows the caregivers or support workers to come across in a better light. Either way, incorrect or withheld information can result in greater difficulties for the health practitioner in coming to an accurate diagnosis and possibly impact on determining the necessary treatment for the individual. Despite the difficulties associated with ensuring the accuracy of third party information, many participants in this research reported using third party information as one of their key tools in overcoming the difficulties they experience when diagnosing mental health difficulties in a person with ID.

**Lack of health practitioner knowledge/experience.** Lack of health practitioner knowledge, expertise and experience has been noted in previous research as being extremely problematic in the area of co-morbid mental health issues for individuals with ID (Dovey & Webb, 2000; Myrbakk & von Tetzchner, 2008; Werner & Stawski, 2012; Mirfin-Veitch & Paris, 2013; Iacono et al, 2003). These difficulties can impact negatively on outcomes for individuals with ID (Dovey & Webb, 2000; Myrbakk & von Tetzchner, 2008; Werner & Stawski, 2012; Mirfin-Veitch & Paris, 2013; Iacono et al, 2003). The difficulties also raise questions about how to address a general lack of health practitioner knowledge and experience (Dovey & Webb, 2000; Myrbakk & von Tetzchner, 2008; Werner & Stawski, 2012; Mirfin-Veitch & Paris, 2013; Iacono et al, 2003).



The data from the online survey, focus group and individual interview all confirmed the above research findings. Despite the acknowledgement of such needs by the NZ Ministry of Health (2013), health practitioners remain frustrated at a lack of placements for students of various professions, time restrictions on university curricula, lack of appropriate and sufficient clinical exposure to individuals with ID and co-morbid mental health issues, and a lack of communication between colleagues in mental health and ID specific teams. In countries such as the UK, ID is identified as a core training module for Clinical Psychology preregistration (Michael, 2008). Other professional bodies, including nursing, midwifery and psychology take a similar stance (Michael, 2008). Findings suggest that this increased exposure and education has resulted in better skills, knowledge, attitudes and values among these health professionals whilst working with people with ID (Michael, 2008).

A number of health practitioners expressed frustration at situations where they perceived that colleagues had made incorrect diagnoses and/or seemed to have a lack of understanding and interest regarding the mental health issues facing individuals with ID. A number suggested greater inter-service collaboration to address these difficulties. This however may potentially increase pressure on health practitioners in the specialist ID field who are already stretched for time and resources. It may also potentially lead to health practitioners not in the ID specialist field increasingly relying on the expertise of specialists without taking responsibility for their own learning and development in this area. Despite these potential limitations, a number of participants recalled their own experiences of drawing on colleagues' experience as crucial in overcoming the challenges associated with making a correct diagnosis of mental health difficulties in people with ID. This is likely to become increasingly important in NZ with the move to a greater reliance on primary health care to provide assessment and care for individuals with an ID who are experiencing co-

morbid mental health disorders (Dovey & Webb, 2000; “Best Practice Advocacy Centre NZ”, 2012; Ministry of Health, 2013).

Some participants also expressed concern that outcomes for individuals with ID and co-morbid mental health issues were worse as a result of lack of experience, expertise and confidence of health practitioners. This is consistent with previous perspective research, which suggests that the mental health outcomes for individuals with ID are worse than for the general population (Pruijssers et al, 2014; Edwards et al, 2007; Jess et al, 2008, Mohr et al, 2002a; Dovey & Webb, 2000; Torr, 2013).

**Atypical presentation.** Previous research has indicated that a client’s presentation varying from the expected is a significant challenge facing health practitioners tasked with diagnosing mental health difficulties in an individual with ID (Edwards et al, 2007; Langlois & Martin, 2008; Spendelow, 2011). Atypical presentations were also discussed by a large number of participants of varied experience as being a challenge they had faced when trying to accurately diagnose mental health difficulties in individuals with an ID.

The nature of the current categorical mental health diagnostic systems presents challenges when individuals experiencing difficulties do not ‘fit’ into said categories (Moss, 2012; Deb et al, 2001). The development of common classification systems such as the DSM-IV-TR, DSM-5 and ICD-10 are based on the general population and were developed with reference to the demographic makeup of the general population (Moss, 2012). Only a small number of individuals with low to below average intelligence would have been included in sample norms used in the development of diagnostic criteria (Moss, 2012).

Given the unique characteristics of individuals with IDs, there are numerous ways in which mental health symptoms can manifest. For example, Hurley (2006) discusses how an individual with ID who has co-morbid depression may have very different thought content compared to an intellectually typical individual, and is more likely to display aggression and

self-harm behaviours (Hurley, 2006). Pruijssers et al (2014) found that increased challenging behaviour appears to be linked to anxiety in individuals with ID. Bouras et al (2004) found in examining schizophrenia-spectrum psychoses in persons with ID and without, that people with ID displayed greater levels of observable psychopathology, more negative symptoms, and functional disability.

A number of diagnostic tools have been developed specifically for the ID population, including the PAS-ADD, Mini PAS-ADD, DC-LD and DM-ID. There is good evidence of their reliability and validity, however some questions remain regarding their diagnostic accuracy, specificity and sensitivity, and standardisation (Mohr et al, 2005). Despite their limitations, at present these tools offer at least some guidance to health practitioners working with an individual with an ID and co-morbid mental health issues. However, in the current research only a small number of participants specifically mentioned using these diagnostic aids. This is of concern for a number of reasons. Firstly, given that over half (56%) of the health practitioners who participated in the research reported having considerable experience working with individuals with an ID, it is of concern that only a small number reported utilising these tools to assist their diagnosis. Secondly, it also appears that health practitioners not experienced in working with individuals with an ID and who have limited knowledge about this population are also not using these tools. Reasons for this lack of use were not specifically explored during the present research, but given the limitations on time and funding mentioned by participants in other aspects of their work, these factors may contribute to their lack of usage, as well as a simple lack of knowledge and training in using these tools.

Other approaches participants mentioned to aid in overcoming the challenges presented by atypical presentations included multiple behavioural observations across time and location, spending time getting to know the individual well and gathering third party information.

**Overshadowing-characteristics of ID/mental health difficulties/challenging behaviour.** A number of health practitioners who participated in this research identified challenges in trying to separate symptoms attributable to the person's ID in and of itself, challenging behaviour, or a mental health disorder. Overshadowing is frequently referred to in the literature as being problematic for health practitioners attempting to diagnose mental health disorders in individuals with ID (Ministry of Health, 2013; Perkins, 2007; Jopp & Keys, 2001; Krahn et al, 2006; McIntyre, 2011). Limitations in an individual's cognitive coping capacities, cognitive flexibility, reasoning and communication all contribute to challenges for health practitioners in determining what is attributable to which difficulty (Taylor et al, 2004). If a health practitioner is either not able to ascertain the underlying factors in the difficulty or incorrectly attributes a difficulty (for example, as merely challenging behaviour rather than an anxiety disorder), this can lead to significant negative ramifications for the individual with ID (Taylor et al, 2004; McIntyre, 2011; Ministry of Health, 2013).

A number of participants also expressed their frustration with colleagues who are less familiar working with individuals with ID and co-morbid psychiatric disorders having a tendency to attribute difficulties to the ID itself or challenging behaviour. One health practitioner in the online survey stated:

*“Adult mental health services in my region do not appear willing to diagnose (or even assess) mental health conditions in clients with ID, assuming that whatever they are presenting with must be due to their disability instead of their mental health.”*

Within NZ, the Ministry of Health (2013) acknowledged that some of the health inequalities experienced by individuals with ID when compared to the general population appear to have occurred due to overshadowing. Suggestions posed by participants during this

research to address these difficulties included encouraging more dialogue and collegial working relationships between ID specific services and general mental health services, increased education during training for health professionals regarding mental health rates for individuals with ID, and how to assess and treat these individuals, as well as taking a holistic approach to assessing an individual with ID.

**Time pressures.** Multiple participants repeatedly discussed time pressures from a variety of sources, including the services they work for, logistical and geographic constraints due to the distribution of NZ health practitioners and individuals with ID, pressure from external agencies such as ACC and the courts. Others described time pressures from support worker and service providers desiring a quick solution to difficulties. For some participants these time pressures made it difficult to complete the tasks expected in their roles to a standard that they were satisfied with. One health practitioner in the focus group outlined their experience:

*“They’ll even let you write a report without seeing somebody now, or they will encourage you to. So I’m not thinking just specifically in the ID context now, but I find having enough time to properly assess one of the ID clients is a real challenge.”*

To a large degree these pressures arise from a general lack of understanding and knowledge of the specific needs of individuals with ID and the complexities and challenges in assessing and diagnosing mental health issues in this population, e.g. some of the characteristics of ID involve reduced cognitive capacity, flexibility and communication difficulties. These difficulties inevitably mean that tasks such as assessment and treatment of mental health issues will take longer than for people without an ID. For health practitioners to complete an adequate assessment, more time must be allowed than is often currently given. One participant in the focus group outlined the time requirements in light of the unique characteristics of individuals with an ID:

*“Most people out there aren’t interested because they don’t know how to adapt. And yet there are resources out there, but it takes time and it’s lots of time. Even the concept of an hour of therapy. Whereas it is a case of a law of thirds... You spend the first third of your session just grounding the person: ‘So, how are you? Remember what we are here for?’ The second third of the session you are actually doing the work, and the last third of the session you are having to recap. So it is a very small window that you are actually lucky if you get one idea across. And then this concept of ‘Well, I will see you next week or next month.’ Then you go through that whole cycle again.”*

The lack of health practitioners experienced in working with this population also leads to this work resting with a few individuals, resulting in high workloads for these health practitioners, with increased pressure on time and resources (Dovey & Webb, 2000; Torr, 2013; Ministry of Health, 2013). Part of the challenge emerging from the results of this research is for service providers, District Health Boards, the NZ Ministry of Health and funding agencies to not only recognise and take on board the unique requirements of the ID population, but also to adapt and adjust service provision to fulfil their needs. In addition challenges are also faced to provide more comprehensive education and training for health practitioners, especially in primary health given the increasing pressure to shift care to this area.

**Societal expectations and understanding of ID.** As discussed in the introduction section of this thesis, the historic understanding, assessment and care of individuals with ID has been fraught with difficulties (Bray, 2003; Milner et al, 2008; Schalock, 2011). Whilst the latter has improved over time, there is still evidence of a lingering legacy of discrimination (O’Brien & Lyle O’Brien, 1995; Bray & Gates, 2003; Chaplin et al, 2010). Implementing effective social reintegration after deinstitutionalisation continues to be a struggle (Bray &

Gates, 2003). This difficulty appears to contribute to continued difficulties for individuals with ID in accessing appropriate support networks within the community and at times accessing adequate health care (Chaplin et al, 2010, Bray & Gates, 2003). These factors in turn perpetuate continued social isolation (within a society), which Chaplin et al (2010) discuss as being involved in a complex two-way relationship with mental health difficulties. The question therefore is should the continued lack of social integration and inequality or mental health needs be addressed first? Alternatively, should both factors be addressed at the same time? O'Brien and Lyle O'Brien (1995) discuss the need for a mutually respected and valued identity and social role with recognition of the contribution that a person brings to their role for community integration to effectively take place. When taking into account the negative effects of mental health difficulties, both the context and the difficulties themselves need to be addressed simultaneously.

The understanding of the difficulties facing individuals with ID, as well as the way in which they are assessed and treated, continues to be problematic today, both in society generally and more specifically among health practitioners (Chaplin et al, 2010; Myrbakk & von Tetzchner, 2008; Mirfin-Veitch & Paris, 2013). Many of the difficulties reported during this research came from more experienced participants who discussed concerns about observing less experienced colleagues, or those they perceived as biased, working in a way they did not approve of. Others raised concerns about having assessed and treated individuals with ID that had been incorrectly diagnosed by a fellow health practitioner. This idea is linked closely to Theme 6 (related to overshadowing), whereby health practitioners struggle to differentiate between difficulties attributable to the ID or to a mental health diagnosis. Some participants outlined their experience of other colleagues' lack of understanding and discrimination towards individuals with ID and co-morbid mental health difficulties:

*“The attitudes and beliefs towards people with an ID, a lack of understanding of the high rate of mental health problems and the fear of not knowing how to assess someone, alongside a lack of understanding surrounding the causes of behaviour in people with ID are very entrenched and result in service denial to the point after working in NZ for 9 years in the disability field, I am completely baffled by what mental health services regard as a mental health problem.”*

This concern is also linked to the understanding held by public and society as to what is seen as normal or abnormal. Mental health referrals can occur as a result of an individual not adhering to the norms and expectations of society and due to their behaviour being perceived as abnormal. Through treatment, it is intended that an individual returns to ‘conform’ to the norms and expectations of society. This contradicts the idea that the rights of the individual with ID have come to the forefront as the driving force behind ideals to achieve a greater quality of life following deinstitutionalisation (Chaplin et al, 2010). These rights include the values of choice, inclusion and independence (Chaplin et al, 2010). O’Brien outlines five core valued human experiences for all people in society (O’Brien, 1989). These include growing in relationships, contributing their skills and attributes, making independent choices, having dignity through a valued social role, and sharing ordinary places and activities in the community (O’Brien, 1989). O’Brien (1989) argues that service provision for individuals with ID should aim to assist in achieving these goals, and that if they are not met they may contribute to continued difficulties experienced by individuals with ID. Yet in many cases, for people with ID it appears that these goals are difficult to achieve (O’Brien, 1989; Bray & Gates, 2003; Chaplin et al, 2010). It appears that it is often not individuals with ID themselves who determine how these goals are achieved, but instead those in positions of power determining what is ‘best’ for these individuals (Chaplin et al, 2010). A potential impact from not meeting these goals and a lack of self determination on the part of the



individual with ID could result in increased complications for the health practitioner in breaking apart difficulties attributable to a lack of basic human social needs such as those described above or underlying mental health difficulties.

The lack of understanding by some health practitioners is compounded by a lack of training and experience with individuals with ID. One participant discussed the need for additional exposure for health practitioners in training to help address lingering social attitudes and biases towards people with ID:

*“So maybe then the more psychology students that get exposure to some time with the ID population will open up their minds to ‘Oh, this person has an ID,’ but you wouldn’t be able to tell from the street that they did, as opposed to somebody rocking in the corner in an institution. I think that might actually open up more Psychologists to being interested in the field.”*

The statement above is considered relevant for all health professions, not just psychology. This is in line with other models, such as that displayed in the UK where some health professions have mandatory core training for working with individuals with an ID (Michael, 2008).

The continued general lack of knowledge and understanding of individuals with ID and their mental health risks, as well as lingering attitudinal biases both by society generally and health professionals, will inevitably lead to persistent difficulties with accurate diagnosis until steps are taken to address these misconceptions. As part of their rights as citizens of NZ, individuals with ID are entitled to appropriate health care, equivalent to that afforded to all citizens of this country. To achieve this, the continued gap in knowledge, skills and understanding about the mental health risks of ID must be addressed.

**Health practitioner frustration and emotive use of language and adjectives.** The strong and emotive language used by a number of participants indicated the degree of

frustration that some health practitioners experience. This frustration appeared in all of the other ten themes outlined. The data collected from the online survey in particular contained some very strongly worded and emotive words. Most of the frustration seemed to centre on the perspective that this population's specific needs are not being met adequately by the current system, that some health practitioners unfamiliar with this population may have other priorities or possible biases, and that not enough is being done to overcome these issues. For example, one participant in the online survey stated:

*“Colleagues of other disciplines in mental health are in general woefully ignorant and sometimes discriminatory and unprofessional in their ill-informed biases against support and understanding of people with ID with mental health diagnosis. Current cross-sectional barriers impede sound diagnostic dialogue.”*

When asked whether there was any additional information that the participant would like to add, another stated:

*“Adult mental health services in my region do not appear willing to diagnose (or even assess) mental health conditions in clients with ID, assuming that whatever they are presenting with must be due to their disability instead of their mental health. There appears to be VERY [Participant's own use of capital letters] poor awareness of the rates of mental health concerns in clients with ID and an unwillingness to address this problem in mainstream mental health. This often results in ID clients not having equal access to mental health services (which is their right), purely as a result of their ID diagnosis.”*

As can be seen from these statements, some health practitioners working within the field feel tremendous passion for the ID population and a great sense of frustration when individuals with an ID do not always receive the level of service that they are entitled to. This perspective is supported by previous research suggesting that the provision of service

afforded to individuals with ID is often below what is acceptable (Mirfin-Veitch & Paris, 2013; Pruijssers et al, 2014). It is possible to also relate these difficulties to the lack of adherence by some health practitioners to the philosophical objective of appropriate service provision. Some of the emotive statements outlined by participants with regard to a lack of interest from health professionals is reflected in prior research, such as that outlined by Kuehn (2003).

The nature of this research, in particular the online survey, enabled participants to provide perspectives without any identifying information. This may have resulted in participants feeling more able to make statements that were strongly worded, emotive and potentially controversial compared to if they were in the presence of others.

**Diagnostic systems - high verbal criteria/taxonomy requirements.** The general diagnostic systems used by health practitioners such as the DSM-IV-TR, DSM-5 and the ICD-10 are not always suitable when assessing an individual with an ID for a co-morbid mental health condition (Moss, 2012). These systems were originally developed in the light of mental health symptoms that individuals of ‘normal’ intellect display. They are largely based on a verbal taxonomy with the assumption that individuals possess both the intellectual capacity and communication skills to understand and respond to verbally posed questions (Moss, 2012). Additionally, some diagnostic criteria specifically taps into changes in language and social skills and are less acknowledging of situations where these are not fully formed in the first instance (Moss, 2012). A number of participants indicated difficulty in assessing individuals with an ID for mental health difficulties as a result of the diagnostic manuals used not being suitable for the ID population. At times these difficulties were in relation to the individual with ID not being able to understand questions being posed; at other times the diagnostic criteria was not relevant given the difficulties the individual displayed. These concerns may also relate to an individual with ID and the health practitioner being

unable to communicate effectively regarding the individual's difficulties. This can make it difficult for health practitioners to correctly identify concerns and problems an individual with ID is experiencing, which in turn then impacts upon the diagnosis and outcome.

As traditional diagnostic criteria were not formulated with regard to the ID population, alternative systems are crucial to enable the correct assessment and treatment of individuals with ID and co-morbid mental health difficulties. This is particularly pertinent when taking into account the elevated rates of mental health difficulties experienced by individuals with ID (Werner & Stawski, 2012; Mohr et al, 2002b; Hughes, 2009). Whilst there are a number of alternative diagnostic tools designed for use individuals with ID, such as the PAS-ADD, the DC-LD and the DM-ID, these are inevitably unable to account for every unique and complex constellation of symptoms that individuals with ID demonstrate. Whilst these tools are useful and practical, they are based on relatively small population groups and require further evaluation regarding validity, reliability, accuracy, specificity, sensitivity and standardisation (Mohr et al, 2005; McIntyre, 2011).

Continued difficulties with accurate diagnosis suggest further work is required in developing other diagnostic systems. These should not only better account for symptoms potentially displayed by individuals with ID, but should also be easier for health practitioners to understand and use with individuals with ID. It is also important to consider and re-evaluate the values held by society, the need for conformity and the role/place of individuals with ID within a community and how these impact upon how we assess and interpret difficulties. In addition, a lack of awareness among health practitioners of the benefit of using such tools indicates further education and training may be required.

**Funding pressures.** Whilst this was the least commonly occurring theme, funding pressures are still a considerable issue to consider in terms of the challenges faced by health practitioners when diagnosing mental health difficulties in individuals with ID. Increasing

pressure on health systems and health practitioners, both in terms of finances and time, inevitably impact upon health practitioners' work. Some participants indicated that funding pressures, alongside pressures from the NZ Ministry of Health to reduce waitlists within their work environments, results in less time and increased pressure to assess and treat greater numbers of individuals with ID. For these health practitioners, this can result in a feeling of not being able to do their job adequately at the expense of the individual with IDs. One participant in the focus group referred to a recent experience that illustrates this issue:

*"I've spent that last few days going through records of a client and writing a report, and I've been paid one hour. So that puts it into some perspective."*

Another participant in the online survey, when asked of any further concerns (that had not been addressed by the main survey) responded:

*"The lack of FTEs [Full time equivalents] for this group of people."*

Given that the Ministry of Health (2013) has recognised the health inequalities experienced by individuals with ID, combined with a lack of confidence and expertise generally among health practitioners outside of specialist ID services, it is perhaps pertinent to consider an increase in resources to train more health practitioners to work with people with ID. This is particularly the case for health practitioners working in primary health, given the increasing reliance and expectations that individuals are first assessed in this setting (Ministry of Health, 2004; Ministry of Health, 2013).

Many participants, both in the online survey and focus group, identified the potential loss of funding for individuals as a pressure. For some health practitioners, this appears to leave them feeling forced into providing a diagnosis they are unsure about when an individual may not present with all the typical signs and symptoms for a disorder. This poses an ethical dilemma for health practitioners who are put in a position of having to label an individual with a mental health disorder that they may not have, or to not provide a diagnosis and face

the loss of potentially necessary funding. Some participants within the focus group suggested that funding and allocation of both resources and services should be based on an individual need basis as opposed to excluding individuals from services unless they fulfil specific service criteria.

#### **4.2 Limitations of the Current Research**

A number of challenges occurred during the present research. One of the most pronounced was the difficulty in accessing health practitioners willing to participate in the research. In particular, accessing GPs to provide them with information about the research and in turn having them willing to participate was problematic. Despite multiple attempts, including a primary health organisation including the study in their regular newsletter delivered to all practices run by the organisation in Christchurch, email and phone contact with surgeries and individual GPs, as well as attempting to visit and speak to GPs at their practice, only three GPs participated in the online survey and only one agreed to participate in an individual interview. This is of considerable concern given the increasing reliance on GPs to provide diagnoses and treatment for individuals with ID and co-morbid mental health difficulties. Potential future research should endeavour to assess the challenges that GPs encounter when diagnosing individuals who have ID with co-morbid mental health issues and how they overcome these.

The initial study aimed to include three to six focus groups, with one to two focus group per health practitioner type (i.e. Psychiatrist, Clinical Psychologist, and GP) divided up by experience of the participants. It became obvious as the research progressed that this would be extremely difficult to achieve due to difficulty gaining health practitioner interest, particularly for those without a specific interest in the ID population, as well as getting health practitioners to take from their busy working lives to attend a focus group.

In light of the difficulty recruiting GPs to complete the online survey, it was decided that focus groups would only be held for Clinical Psychologists and Psychiatrists. GPs would instead be invited to participate in an individual interview with the researcher at a time and place of their convenience. As noted above, only one GP agreed to meet with the researcher to participate in an individual interview.

In addition, when recruiting participants for the focus groups, it became evident that the number of health practitioners choosing to participate was not as high as originally hoped. Consequently, only one focus group took place. No Psychiatrists chose to participate in the focus group, meaning only Clinical Psychologists and Psychologists took part. Despite this, a considerable number of Psychiatrists took part in the online survey, providing valuable information and insight into the challenges they face as health practitioners and how they overcome such challenges.

Just over half of the participants (56%) who took part in this research were experienced in working with individuals with ID, but most (83%) were confident in working with individuals with an ID. Given previous research, such as Dovey and Webb's (2000) study of GPs in NZ and more recently Mirfin-Veitch and Paris' (2013) review of the literature which suggests the majority of health practitioners do not feel confident in working with this population, the participants of this research may not be representative of health practitioners as a whole group. The data collected may not represent accurately the difficulties that less confident health practitioners face. This may have arisen due to a variety of reasons, such as lack of interest in the project, a perception that the research was not applicable to them, not identifying the research topic as an issue, difficulty in accessing the online survey due to the invitation being in print form (in the case of distribution to the primary health organisation health practitioners), or lack of time to participate in research. In

turn, how health practitioners overcome these difficulties is also likely to differ depending on their experience and confidence in working with individuals who have an ID.

The responses of health practitioners during the focus group were analysed with regard to emerging codes and themes. Whilst the focus group involved interactions between participants with varying experience and varying clinical focus it is possible that further research involving an examination of interactional patterns between participants would be useful which was largely beyond the scope of this project.

The possible relationship between approaches to diagnostic challenges versus the number of years experience of health practitioners was not fully explored in this study. In retrospect the study may have benefited from asking specific questions particularly during the online survey regarding health practitioners years of experience in working with individuals with ID.

### **4.3 Recommendations**

**Use of a holistic, contextual, flexible and open approach when assessing mental health diagnoses in individuals with ID.** Results from this research suggest that it is crucial for health practitioners to take a holistic and contextual view of the individual with an ID, their life and experiences. Flexibility in approach is seen as important as many of the standard strategies in assessment are likely to be insufficient with this population. Behavioural observation and alternative sources of information are crucial to adequately ascertain difficulties facing an individual.

**Use of diagnostic systems and tools developed specifically for use with individuals with ID.** It is recommended that health practitioners use systems and tools that are specifically designed to measure ID and co-morbid mental health issues. These include (but are not limited) to PAS-ADD, Mini PAS-ADD, DM-ID, DC-LD and the Glasgow Depression Scale. It is crucial that health practitioners do not rely only on general diagnostic



systems that do not account for the unique attributes and characteristics of the ID population. In order for health practitioners to become aware of these tools, it is imperative that training institutions and the NZ Ministry of Health promote their use and outline the risks of using tools and systems not developed for use with this population.

**Development of a best practice guideline and the efficacy of the diagnostic systems and tools developed specifically for use with individuals with ID.** It is recommended that future researchers consider developing a best practice guideline, with references to the efficacy of diagnostic systems and tools developed specifically for use with individuals with ID to help guide health practitioners to appropriate resources. Similar guidelines and reviews of tools have been developed to good effect by other areas of mental health.

**Health practitioners should take every step possible to liaise with experts and specialists in the field when facing difficulties in diagnosis.** Throughout this research many participants discussed the need for more open dialogue between colleagues and inter-collegial support for less experienced health practitioners. Given the unique attributes of individuals with ID and the specific challenges in this area, guidance from experienced colleagues would aid health practitioners who are less experienced. It is recommended that any health practitioner experiencing difficulties when attempting to diagnose a mental health disorder in a person with ID seek appropriate advice from other more experienced and/or specialised colleagues.

**More access to ID specific training for health practitioners.** It is recommended that both the NZ Ministry of Health and education providers ensure that all health training programmes provide adequate training on ID and mental health within the health practitioner training programmes. This would not only increase the accuracy of health practitioner

diagnosis in this population and reduce the inequity of health difficulties faced by individuals with ID, but also continue to break down societal and attitudinal barriers.

**Further research into the specific difficulties facing GPs in primary health care positions regarding the challenges faced when assessing mental health difficulties in individuals with ID.** Due to the limited number of GPs who took part in this research project, it is recommended a future repeat study examining the unique challenges faced by health practitioners in primary care roles is conducted. This is particularly important given the limited time and funding resources in primary health care, as well as the increasing reliance on primary health care practitioners in assessing, diagnosing and treating basic mental health difficulties for all members of the population, no matter what their intellectual capacity (Ministry of Health, 2012; Ministry of Health, 2013; Ministry of Health, 2015).

**Review of funding for specialist health practitioners working with individuals with ID and co-morbid mental health difficulties.** The evidence from this research indicates that a review of the current full time equivalents (FTEs) per ID capita is needed. This is supported by the NZ Ministry of Health acknowledgement of the health inequalities in this field (Ministry of Health, 2013), as well as assessment demands and the research findings of Mirfin-Veitch and Paris (2013); Jess et al, (2008); Edwards et al, (2007), and Mohr et al, (2002a).

#### **4.4 Summary**

The diagnosis of mental health difficulties in individuals with ID poses significant challenges for health practitioners working in the field. Increasingly the number of health practitioners in primary health roles who are likely to come across, assess and treat mental health difficulties in individuals with ID is rising (Ministry of Health, 2004; Ministry of Health, 2013). This is a result of The Primary Mental Health Initiatives (PMHI), established in 2004 by the NZ Ministry of Health as a means of increasing funding in the delivery and infrastructure of

mental health services in the primary health sector (Dowell et al, 2009). The Ministry of Health (2015) recommends that the primary health sector for all individuals, regardless of IQ should adopt a stepped care approach to service provision. They outline that stepped care is a system of delivering and monitoring treatments so that the treatment that is most effective, yet least resource intensive, is delivered to patients first (Ministry of Health, 2015).

Overstretched resources at the secondary and tertiary level and the directive issued to these services to reduce wait times by the Ministry of Health (2012), in line with the mental health and addiction service development plan 2012-2017, have also resulted in increasingly reliance on primary health practitioners to provide such services, where perhaps in the past they may not have had to. Additionally, the deinstitutionalisation and devolvement of care from specialist secondary and tertiary services to primary health, in line with the objectives outlined by the Ministry of Health, has resulted in a dispersal of centralised health practitioners' knowledge. These factors continue to pose significant challenges to health practitioners to achieve effective assessment for individuals with ID and co-morbid mental health issues.

This study has provided insight into and further supports previously identified challenges experienced by health practitioners when trying to diagnose mental health difficulties in individuals with ID. Additionally, some ways in which experienced health practitioners have attempted to deal with these challenges have been identified.

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## APPENDIX A

University of Canterbury Human Ethics Committee application (reference number:  
HEC application 2013/80/LR)



## HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2013/80/LR

16 September 2013

Karen Davies  
Department of Psychology  
UNIVERSITY OF CANTERBURY

Dear Karen

Thank you for forwarding your Human Ethics Committee Low Risk application for your research proposal "Axis I diagnoses in persons with an intellectual disability: how clinicians overcome the challenges".

I am pleased to advise that this application has been reviewed and I confirm support of the Department's approval for this project.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 14 September 2013.

With best wishes for your project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L MacDonald'.

Lindsey MacDonald  
*Chair, Human Ethics Committee*



## APPENDIX B

## Amended Ethics Committee Application HEC application (2013/80/LR)



## HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2013/80/LR

1 September 2014

Karen Davies  
Department of Psychology  
UNIVERSITY OF CANTERBURY

Dear Karen

Thank you for your request for an amendment to your research proposal “Axis I diagnoses in persons with an intellectual disability: how clinicians overcome the challenges” as outlined in your email dated 29 August 2014.

I am pleased to advise that this request has been considered and approved by the Human Ethics Committee.

Yours sincerely

A handwritten signature in black ink, appearing to read 'L. MacDonald'.

Lindsey MacDonald  
*Chair, Human Ethics Committee*

## APPENDIX C

**Research approval (Project ref: RAE0025) and conditions of approval provided by Pegasus Health Charitable Ltd**

## Research Audit Evaluation



7 May 2014

Karen Davies  
Department of Psychology  
University of Canterbury  
Private Bag 4800  
CHRISTCHURCH 8140

Dear Ms Davies

Thank you for your application for Pegasus Health research support ref: RAE0025

We are pleased to advise you that your request has been approved, with universal support from the committee. The committee agreed that Pegasus support will be in the form of information distribution. We are happy to distribute information for you about your research and how to participate via the Pegasus 'Blue Bag' communication that goes to every GP each week. This is prioritized communication containing a small number of items and highlights Pegasus endorsement, increasing the likely rate of participation over a standard mailout.

We will need for our records copies of:

- The final study protocol when completed.
- Any ethics approval changes or approvals for any extensions)
- Copies of any other subsequent correspondence with the ethics committee including annual reports.
- A final report on the study
- A copy of any publications resulting from the research

The following person is the designated contact person within the organization for distribution of the project materials: [elena.novitchkova@pegasus.org.nz](mailto:elena.novitchkova@pegasus.org.nz)

We wish you well with your research. Please contact the committee if we can offer any further advice that would assist you.

Yours sincerely

Assoc. Prof. Derelie Mangin  
Chair Research Audit and Evaluation Committee

## APPENDIX D

### Online survey participant information and consent form

*(Please note this information sheet will be accessed on the qualtrics survey online and as such will be formatted according to the qualtrics website. In order to access the survey the participant will need to select the yes button, which is at the bottom of this information sheet- please see below)*

Informed Consent Form- Axis I diagnoses in persons with an Intellectual Disability: How clinicians overcome the difficulties

#### Introduction and purpose of this study

The information on this consent page outlines the aims of this research as well as the process that will take place should you choose to participate in the research.

Individuals with Intellectual Disabilities (ID's) are widely acknowledged to be at greater risk of developing Axis I psychological disorders than the general population. Yet in prior studies, clinicians have indicated their belief that the ID population is not well served by the current mental health services offered.

This questionnaire is the first stage in a research study that will involve the gathering and analysis of data regarding clinicians' perspectives on the diagnosis of people with an ID in terms of axis I disorders, and the challenges that occur when making these decisions. As a clinician who is currently, has in the past or may in the future potentially be working with individuals with an ID as well as being involved in the diagnosis of Axis I disorders for these individuals, your perspectives and experiences in the difficulties in coming to a diagnosis and how you have or potentially may overcome these challenges are valued and appreciated.

(Please note a second stage of this project will take place at a later date which will involve a number of focus groups taking place which will aim to expand and provide greater depth in the exploration of the difficulties clinicians face in diagnosing Axis I disorders in persons with an ID. You may or may not be approached in the future to participate in a focus group, however as with the first stage of the research project you are not under any obligation to participate with participation being entirely voluntary).

Please read this information consent form carefully. If you would like to participate in the research please indicate your acceptance by printing a copy of this page and clicking the yes button below. Please note that you may choose to withdraw from the research at any time during the survey with no consequences to yourself. Please note also that you are not being asked to break the confidentiality of your clients in any way.

How did you get chosen to take part in the research?

This project aims to draw information from clinicians with varied experience and expertise in working with individuals who have an ID with Axis I psychological disorders. These include Psychiatrists, Psychologists and General Practitioners. Various groups including special interest groups in the area of ID, the College of Clinical Psychologists, The Royal College of Australian & New Zealand Psychiatrists, Psychiatrists in the Canterbury region and General Practitioners associated with the primary health organisation Pegasus Health have been approached with or invited to participate with approval from the organisations in question. As such you have received this invitation to participate as a result of falling in or being a part of one of the groups or organisations listed above.

### Procedures

Should you choose to take part the survey will consist of a number of yes/ no questions, multiple choice, and open ended questions which should take approximately 20 minutes in total to answer. Questions are designed to determine your experience in working with individuals with ID's, your experience of diagnosing Axis I disorders in persons with an ID, any challenges you experienced in during the diagnosis process or think you may face if you do not have experience working with individuals with an ID as well as Axis I psychological disorders and how you overcame these difficulties. This questionnaire will be conducted with an online Qualtrics-created survey.

### Risks/Discomforts

Risks are minimal should you choose to take part in this study. However, you may feel uncomfortable at times in answering specific questions. Please note that you may skip any questions you do not feel comfortable answering or withdraw from the research entirely.

### Benefits

There are no direct benefits for participants. However, it is hoped that through your participation, we can discover some of the difficulties that clinicians experience in diagnosing individuals who have an ID with an Axis I disorder as well as how clinicians overcome these difficulties. It is hoped that this information may be of use to clinicians in the future faced with similar situations.

### Confidentiality

Results gathered from this research will be combined together once we have gathered all the data. These results may be published and presented at conferences. However, confidentiality of participants will be preserved.

All questionnaires will be held securely and will only be accessible by the researcher(s) (Karen Davies), Senior Supervisor (Dr Eileen Britt) and co-supervisor (Chris Daffue). The data collected will be stored in the HIPPA-compliant, Qualtrics-secure database until it has been deleted by the primary researcher (Karen Davies).

### Participation

Participation in this research study is completely voluntary. You have the right to withdraw at anytime or decline to participate without any consequences whilst completing the survey. If

you do not wish to participate please indicate this by ticking the no button below. If you desire to withdraw from the survey at any stage please close your internet browser which will exit you from the survey. Please note that when your survey is submitted you will no longer be able to withdraw your survey data as the surveys are completely anonymous and your data will not be able to be identified.

#### Questions about the Research

If you have questions regarding this study, please contact:

Karen Davies (Clinical Psychology trainee and masters thesis student)  
Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch, 8140  
karen.davies@pg.canterbury.ac.nz

or alternatively,

Dr Eileen Britt (Senior Supervisor)  
Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch, 8140  
+64 3 364 2987, ext. 7195  
eileen.britt@canterbury.ac.nz

*This project has been reviewed and approved by the Department of Psychology and the University of Canterbury Human Ethics Committee as a low risk research project.*

If you have any complaints, please contact the Human Ethics Committee at Okeover House, University of Canterbury, Private Bag 4800, Christchurch 8140, or email: human-ethics@canterbury.ac.nz

Q1. I have read, understood, and printed a copy of, the above consent form and desire of my own free will to participate in this study.

Yes

No

## **APPENDIX E**

### **Online survey questions**

#### **Masters Survey Questions**

(Please note as this survey is administered on Qualtrics, questions will be presented according to the Qualtrics format)

**Q.1 What is your current professional registration?**

**Q.2 Have you ever professionally worked with an individual with an Intellectual Disability (ID)?**

**Yes**

**No**

**Q.3 (Only if yes is selected on Q.2)**

**How much of your current position and experience involves working with individuals with an ID?**

**1.Extensive**

**2.A lot**

**3.Some**

**4.A little**

**5.Minimal**

**Q.4 How confident do you feel working with individuals with intellectual disabilities?**

**1.Very confident**

**2. Mostly confident**

**3. Sometimes confident**

**4. Mostly unconfident**

**5. Very unconfident**

**Q.5 Do you have any formal experience in diagnosing psychiatric disorders in individuals with an ID?**

**Yes**

**No**

**Q.6 (Only if yes is selected on Q.5)**

**How much of your current job requirement involves diagnosing psychiatric disorders in individuals with an ID?**

**1. Extensive**

**2. A lot**

**3. Some**

**4. A little**

**5.Minimal**

## 6.Unsure

**Q.7 How much time do you generally have in order to undertake a full formal assessment in order to make a mental health / psychiatric diagnosis?**

**Q.8 When making such a diagnosis with a person with an intellectual disability, how much opportunity do you have to explore the individual's background, support systems and life experience?**

**Q.9 Is there pressure on you as a clinician to make a formal mental health / psychiatric diagnosis?**

**Q.10 How confident do you feel in diagnosing mental health / psychiatric disorders in individuals who have an ID?**

**Q.11 In cases where you have diagnosed mental health / psychiatric disorders in individuals with an ID, did you experience any challenges in coming to a diagnosis?**

Yes

No

**Q.12 (Only if yes is selected on Q.11 )  
What challenges did you experience?**

**Q.13 What formal tools/systems do you use in developing a mental health/psychiatric diagnosis in individuals with an intellectual disability?**

**Q.14 When you have been uncertain in making a diagnosis using the DMS-IV what has been the formal outcome for the client? What do you do?**

**Q.15 Do you anticipate any uncertainties in making a mental health diagnosis for individuals with intellectual disabilities when using the DSM-5? What do you do?**

**Q.16 In cases where you have struggled to come to a mental health / psychiatric diagnosis for a person with an intellectual disability, what steps do you usually take to address these difficulties?**

**Q.17 If you rely on a third party for information such as a caregiver and/or a parent or family member, how do you ensure their response accuracy?**

**Q.18 How do you control for or get around the above third party's potential bias or lack of accuracy?**

**Q.19 When trying to ascertain an individual's mental status how much importance would you place on the role of expressive communication?**

**Q.20 How do you formally control for the impact of physical disabilities on an individual's expressive communication ability e.g. when assessing someone who has cerebral palsy, speech disorders etc?**

**Q.21 When trying to ascertain an individual's mental status how much importance would place on the role of receptive communication?**

**Q.22 How do you formally control for the impact of physical disabilities on an individual's receptive communication ability e.g. when assessing someone who has attention difficulties, processing difficulties etc?**

**Q.23 When diagnostic criteria call for an individual's description of thoughts and/or feelings and they are unable to provide this information, how do you get around this?**

**Q.24 Do you replace the criteria with anything else?**

**Q.25 With regard to Major Depressive Disorder, how would you formally and reliably check if an individual with an intellectual disability has feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)?**

**Q.26 With regard to Generalised Anxiety Disorder, how would you determine if "The person finds it difficult to control their worry"?**

**Q.27 With regard to Paranoid Personality Disorder, how would you check whether the individual with an intellectual disability "is reluctant to confide in others because of unwarranted fear that the information will be used maliciously against him or her"?**

**Q.28 How would you check to establish whether the individual with an intellectual disability is experiencing delusions?**

**Q.29 Do you, or have you in the past, referred individuals who have an ID with a suspected mental health issue / psychiatric disorder on to another health professional or team?**

**Q.30 (Only if yes is selected on Q.27)**

**What circumstances/cases would lead you to refer a client on to another health professional/ team?**

**Q.31 Is there any other information that has not been covered in the questions above that you would like to add in regards to your experience of diagnosing mental health/psychiatric disorders in individuals with ID's?**

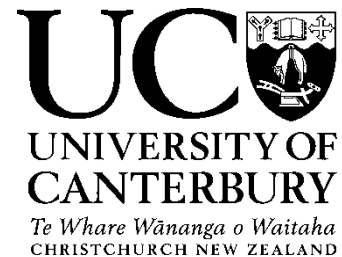


## APPENDIX F

### Focus group participant information

#### College of Science

Department of Psychology  
 Tel: +64 3 364 2902, Fax: + 64 364 2181  
 Email: [office@psychology.ac.nz](mailto:office@psychology.ac.nz)  
[www.psyc.canterbury.ac.nz](http://www.psyc.canterbury.ac.nz)



Date: 22/08/2014

#### Participant Information Sheet

**Title:** Mental health diagnoses in persons with an ID: How clinicians overcome the challenges

The information on this sheet outlines what is involved in the research. Please read this carefully. If you would like to attend the focus group, please **sign the consent form** also include. There will be one session held on the 15/09/2014 between 8.30-10.00am in the Psychology staff room, 2<sup>nd</sup> floor of the Psychology building at The University of Canterbury.

This session may not take the full hour and a half, but this allows for morning tea. If you choose to take part, after you have returned your consent form (a return envelope is included in this package), we will mail you a few days in advance with a **parking coupon and a map** showing you where to go. The focus groups will be held in the Psychology building at the **University of Canterbury**. The focus groups will be facilitated by Karen Davies (Clinical Psychology trainee and masters student).

#### **What is the purpose of this study?**

Individuals with Intellectual Disabilities (ID's) are widely acknowledged to be at greater risk of developing co-morbid mental health disorders than the general population. Yet in prior studies, clinicians have indicated their belief that the ID population is not well served by the current mental health services offered.

The focus group is the second stage in a research study that involves the gathering and analysis of data regarding clinicians' perspectives on the challenges in diagnosing co-morbid mental health disorders for individuals with an ID, and how they overcome these challenges. As a clinician who is currently, has in the past or may in the future potentially be working with individuals with an ID as well as being involved in the diagnosis of co-morbid mental health disorders in these individuals, your perspectives and experiences are valued and appreciated. In time it is hoped that the results from this study will help to guide other clinicians who are experiencing difficulties with diagnosing co-morbid mental health disorders for individuals with an ID.

### **How did you get chosen to take part in the research?**

This project aims to draw information from clinicians with varied experience and expertise in working with individuals who have an ID with co-morbid mental health disorders. These include Psychiatrists, Psychologists and General Practitioners. Various groups including special interest groups in the area of ID, the College of Clinical Psychologists, The Royal College of Australian & New Zealand Psychiatrists, Psychiatrists in the Canterbury region and General Practitioners associated with the primary health organisation Pegasus Health have been approached with or invited to participate with approval from the organisations in question. As such you have received this invitation to participate as a result being a part of one of the groups or organisations listed above.

### **Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do choose to take part you can withdraw at any time, even during the focus group session. However, as a clinician you have important information about the difficulties you may have experienced and how you overcame these and your input would be of great value.

### **Potential Risks/Discomforts**

Risks are minimal should you choose to take part in this study. However, you may feel uncomfortable at times in answering specific questions. Please note that you are not obliged to respond to any questions you do not feel comfortable answering or withdraw from the research entirely. Please note also that you are not being asked to break the confidentiality of your clients in any way.

### **Benefits**

There are no direct benefits for participants. However, it is hoped that through your participation, we can discover some of the difficulties that clinicians experience in diagnosing individuals who have an ID with an co-morbid mental health disorder as well as how clinicians overcome these difficulties. It is hoped that this information may be of use to clinicians in the future faced with similar situations.

### **Confidentiality**

Results gathered from these focus groups will be combined together with data gathered from the initial online survey, which was the first stage of this project. These results may be published and presented at conferences. **However, confidentiality of participants will be preserved.**

All information collected from the focus groups will be held securely at the University of Canterbury and will only be accessible by the researcher(s) (Karen Davies), Senior Supervisor (Dr Eileen Britt) and co-supervisor (Chris Daffue).

### **Transcript of focus group**

A transcript of the focus group you participate in will be available to you should you wish to review the information covered in the session. Please contact Karen Davies on the below contact details to request a transcript.

### **Questions about the Research**

If you have questions regarding this study, please contact:

Karen Davies (Clinical Psychology trainee and masters thesis student)

Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch, 8140  
karen.davies@pg.canterbury.ac.nz

or alternatively,

Dr Eileen Britt (Senior Supervisor)  
Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch, 8140  
+64 3 364 2987, ext. 7195  
eileen.britt@canterbury.ac.nz

***This project has been reviewed and approved by the Department of Psychology and the University of Canterbury Human Ethics Committee as a low risk research project.***

If you have any complaints, please contact the Human Ethics Committee at Okeover House, University of Canterbury, Private Bag 4800, Christchurch 8140, or email: human-ethics@canterbury.ac.nz

## APPENDIX G

### Focus group participant consent form

College of Science

Department of Psychology

Tel: +64 3 364 2902, Fax: + 64 364 2181

Email: [office@psychology.ac.nz](mailto:office@psychology.ac.nz)

[www.psyc.canterbury.ac.nz](http://www.psyc.canterbury.ac.nz)



### Consent Form

**Title of Project:** Mental health diagnoses in persons with an ID: How clinicians overcome the challenges

### Name of Researchers:

Karen Davies (Clinical Psychology Trainee & Masters student, University of Canterbury); Dr Eileen Britt (Clinical Psychologist/Senior lecturer, University of Canterbury); Chris Daffue (Senior Clinical Psychologist, Canterbury District Health Board).

**Please tick box**

1. I confirm that I have read and understand the information sheet dated 22/08/2014 for the above study. I have had the opportunity to consider the information, and have been given a contact if I have any questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and my withdrawal will have no negative consequences on me. ☐
3. I understand that my participation is confidential, i.e., that any information provided by me is confidential and there will be no identifying information on the report generated as a result of the focus group I participate in. ☐
4. I agree to take part in the following study. ☐
5. I consent that my data (unidentifiable) be merged with all the other data for publication. ☐

---

Name of participant

---

Signature

---

Date

*This project has been reviewed and approved by the Department of Psychology and the University of Canterbury Human Ethics Committee as a low risk research project. If you have any complaints, please contact the Human Ethics Committee at Okeover House, University of Canterbury, Private Bag 4800, Christchurch 8140, or email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)*

## APPENDIX H

### Individual interview participant information College of Science

Department of Psychology  
Tel: +64 3 364 2902, Fax: + 64 364 2181  
Email: [office@psychology.ac.nz](mailto:office@psychology.ac.nz)  
[www.psyc.canterbury.ac.nz](http://www.psyc.canterbury.ac.nz)

Date: 22/08/2014



### Participant Information Sheet

**Title:** Mental health diagnoses in persons with an ID: How clinicians overcome the challenges

The information on this sheet outlines what is involved in the research. Please read this carefully. If you would like to participate in an individual interview please also sign the consent form included. These interviews will be held at a location convenient to yourself, for instance at your surgery.

The interview will likely take between **30 minutes to 1 hour** in duration. The interview will be conducted by Karen Davies (Clinical Psychology trainee and master's student).

#### **What is the purpose of this study?**

Individuals with Intellectual Disabilities (ID's) are widely acknowledged to be at greater risk of developing co-morbid mental health disorders than the general population. Yet in prior studies, clinicians have indicated their belief that the ID population is not well served by the current mental health services offered.

These individual interviews are the second stage in a research study that involves the gathering and analysis of data regarding clinicians' perspectives on the challenges in diagnosing co-morbid mental health disorders for individuals with an ID, and how they overcome these challenges. As a clinician who is currently, has in the past or may in the future potentially be working with individuals with an ID as well as being involved in the diagnosis of co-morbid mental health disorders in these individuals, your perspectives and experiences are valued and appreciated. In time it is hoped that the results from this study will help to guide other clinicians who are experiencing difficulties with diagnosing co-morbid mental health disorders for individuals with an ID.

#### **How did you get chosen to take part in the research?**

This project aims to draw information from clinicians with varied experience and expertise in working with individuals who have an ID with co-morbid mental health disorders. These include Psychiatrists, Psychologists and General Practitioners. Various groups including special interest groups in the area of ID, the College of Clinical Psychologists, The Royal College of Australian & New Zealand Psychiatrists, Psychiatrists in the Canterbury region and General Practitioners (GP) were approached to take part. You have received this invitation to participate as a result of being a GP working in the Canterbury area.

**Do I have to take part?**

No. It is up to you to decide whether or not to take part. If you do choose to take part you can withdraw at any time, even during the individual interview. However, as a clinician you have important information about the difficulties you may have experienced and how you overcame these and your input would be of great value.

**Potential Risks/Discomforts**

Risks are minimal should you choose to take part in this study. However, you may feel uncomfortable at times in answering specific questions. Please note that you are not obliged to respond to any questions you do not feel comfortable answering or withdraw from the research entirely. Please note also that you are not being asked to break the confidentiality of your clients in any way.

**Benefits**

There are no direct benefits for participants. However, it is hoped that through your participation, we can discover some of the difficulties that clinicians experience in diagnosing individuals who have an ID with an co-morbid mental health disorder as well as how clinicians overcome these difficulties. It is hoped that this information may be of use to clinicians in the future faced with similar situations.

**Confidentiality**

Results gathered from these interviews will be combined together with data gathered from the initial online survey, which was the first stage of this project and focus groups which were held for other clinicians. These results may be published and presented at conferences.

**However, confidentiality of participants will be preserved.**

All information collected from the individual interviews will be held securely at the University of Canterbury and will only be accessible by the researcher(s) (Karen Davies), Senior Supervisor (Dr Eileen Britt) and co-supervisor (Chris Daffue).

**Questions about the Research**

If you have questions regarding this study, please contact:

Karen Davies (Clinical Psychology trainee and masters thesis student)  
Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch, 8140  
karen.davies@pg.canterbury.ac.nz

or alternatively,

Dr Eileen Britt (Senior Supervisor)  
Department of Psychology, University of Canterbury, Private Bag 4800, Christchurch, 8140  
+64 3 364 2987, ext. 7195  
eileen.britt@canterbury.ac.nz

***This project has been reviewed and approved by the Department of Psychology and the University of Canterbury Human Ethics Committee as a low risk research project.***

If you have any complaints, please contact the Human Ethics Committee at Okeover House, University of Canterbury, Private Bag 4800, Christchurch 8140, or email: human-ethics@canterbury.ac.nz

## APPENDIX I

### Individual interview participant consent form

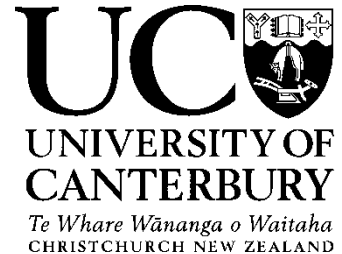
College of Science

Department of Psychology

Tel: +64 3 364 2902, Fax: + 64 364 2181

Email: [office@psychology.ac.nz](mailto:office@psychology.ac.nz)

[www.psyc.canterbury.ac.nz](http://www.psyc.canterbury.ac.nz)



#### Consent Form

Title of Project: Mental health diagnoses in persons with an ID: How clinicians overcome the challenges

#### Name of Researchers:

Karen Davies (Clinical Psychology Trainee & Masters student, University of Canterbury); Dr Eileen Britt (Clinical Psychologist/Senior lecturer, University of Canterbury); Chris Daffue (Senior Clinical Psychologist, Canterbury District Health Board).

Please tick box

1. I confirm that I have read and understand the information sheet dated 22/08/2014 for the above study. I have had the opportunity to consider the information, and have been given a contact if I have any questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and my withdrawal will have no negative consequences on me. ☐
3. I understand that my participation is confidential, i.e., that any information provided by me is confidential and there will be no identifying information on the report generated as a result of the individual interview I participate in. ☐
4. I agree to take part in the following study. ☐
5. I consent that my data (unidentifiable) be merged with all the other data for publication. ☐

---

Name of participant

---

Signature

---

Date

*This project has been reviewed and approved by the Department of Psychology and the University of Canterbury Human Ethics Committee as a low risk research project. If you have any complaints, please contact the Human Ethics Committee at Okeover House, University of Canterbury, Private Bag 4800, Christchurch 8140, or email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)*

## APPENDIX J

### Focus group questions

1. What has been your experience of some of the key challenges in diagnosing a co-morbid psychiatric disorder when working with someone who has an ID?
2. How do you overcome these challenges?
3. Does providing a psychiatric diagnosis in anyway perpetuate stereotypical views of people with ID (either positive or negative)? ('mad' 'cute downs syndrome')
4. In your experience are some diagnostic systems more user friendly/flexible/adaptable?
5. Are there some that are less user friendly/flexible/adaptable?
6. What diagnostic systems do you use (DSM-IV, DSM-5, ICD-10)?
7. Do you think there is room for criteria to be softened in order to provide a diagnosis?
8. If you are unsure about a diagnosis what are the steps you take?
9. In your experience to what extent does having a referral come from an individual other than the client, shape how you approach diagnosis? (i.e. support service, justice system).

Broad areas for possible exploration: Verbal diagnostic system, Communication, atypical presentation, 3<sup>rd</sup> party information, understanding from other clinician